

The place of death among people with dementia in Finland
–The change from 1998 to 2013

Yaeko Masuchi

ABSTRACT

University of Tampere

School of Health Sciences

MASUCHI, YAEKO: THE PLACE OF DEATH AMONG PEOPLE WITH DEMENTIA
IN FINLAND –THE CHANGE FROM 1998 TO 2013

Master's Thesis, 63 pages, 2 Appendices

Supervisors: Mari Aaltonen, Ph D, University of Tampere, Finland

Health Sciences (Public Health)

December 2016

Background: The prevalence of dementia has been expanding largely and quickly among the developed countries. The increasing prevalence of dementia is a significant problem, especially since there is currently no cure available for this disease. Dementia is the most prominent disease among older people associated with a loss of independent function and autonomy, which affects not only the patients but also their family members. Dementia becomes an important cause of disability and death worldwide. The quality of care toward and at the end of life care has discussed to be improved for benefits of not only people with dementia but also caregivers alongside the increasing prevalence of dementia in the older population. The place of death is suggested as a quality indicator for the end-of-life care. Finland is growing old most rapidly among EU countries. Details of the place of death for people with dementia in Finland have not been reported yet.

Aims: The aim of this study was to reveal where people with dementia die in Finland, and what extent the frequency of different places of death has changed over time.

Data: Data of the places of death of people with dementia were derived from Finnish national health and social care registers.

Data covered all those who died at the age of over 70 years had dementia in the study years 1998 and 2002-2013, and a 40% random sample in the years 1999-2001 (N=140034).

Methods and Results: Descriptive analysis and logistic regression analysis were done using the IBM SPSS statistics. During the study period, the frequency of dementia increased from 22% to 33.9%. Men with dementia died more often at an earlier age (aged 70-79) than women who died more frequently at a later age (aged 90+). During the study years 1998-2013, the most frequent place of death was the primary care hospital (i.e. the health center), followed by nursing home and sheltered housing with 24-hour assistance. Dying at home or specialized hospitals was rare. During the study years, dying in the hospital decreased. Dying in the long-term care facility increased. The sheltered housing with 24-hour assistance became a more frequent place of death in Finland.

Conclusions: Trends in places of death has changed from institutional care to outpatient long-term care in Finland last decades. Death at home and specialized hospitals for people with dementia remained infrequent in Finland. Even nearly half of people with dementia died at the primary care hospital, but recently the trend of dying at long-term care facility, especially sheltered housing with 24-hour assistance increased in Finland.

Keywords: dementia, end-of-life care, place of death, long-term care setting, health center (same as primary care hospital in other countries), and the sheltered housing with 24-hour assistance

Table of Contents

Chapter 1: Introduction	9
1.1 Background: The importance of studying of the place of death for people with dementia	9
1.2 Dementia	12
1.3 Care at the end of life for people with dementia	14
1.4 Place of death	17
1.5 Dementia trend in Finland	20
1.6 Health and social care services in Finland	21
 Chapter 2: Aims and research questions	 24
 Chapter 3: Data and Methods	 25
3.1 Data sources: registers	25
3.2 Study population	26
3.3 Methods.....	26
 Chapter 4: Results	 28
4.1 Description of study population.....	28
4.2 Place of death	30
4.3 Differences between age groups and men and women	32
4.4 Regression analysis of the association between risk factors and place of death	36
 Chapter 5: Discussion and Conclusions	 39
5.1 Summary of the main findings.....	39
5.2 The relationship of my research to the previous researches	41
5.3 The strengths and weaknesses	44
5.4 Further research	45

Chapter 6: Recommendations for policy or practice	47
References	49
Appendix	60

Acknowledgements

I came to Finland from the USA with a high motivation to learn about Nordic Health and Social care system in detail, and I would contribute to solving our chaos on health care system for the nation and population when I go back. Currently, this is the most severe problem we are facing in the USA. I would introduce knowledge I have learned in the Nordic countries and create some ideas to improve our situation.

Finnish educational system is fantastic for supporting the international student offering excellent English-based education. At the University of Tampere, School of Health Sciences, and also Gerontology group with leadership by Prof. Marja Julhä I achieved my goal of learning Nordic Health and Social care system in this short period. I indeed appreciate Finnish international education. I also deeply appreciated International coordinator at the University of Tampere, School of Health Sciences, Ms. Catarina Ståhle-Nieminen, without her active and efficient support I could not solve many difficulties I faced here to continue study and personal matter as well. I believe I am not only an international student acknowledge to Ms. Cata's support in the School of Health Sciences.

Completing my Master research and thesis, I genuinely appreciated the strong support and encouragement of those who have contributed to this study. Especially my thesis advisor, supervisor Mari Aaltonen, Ph.D. at the University of Tampere, School of Health Sciences, Gerontology group, who is another amazing scientist similarly Prof. Marja Julhä. She always gave me quickly, expert and heartworm advice and comments to my work. Without her strong mentorship, I could not finish. Needless to say, Professor Marja Jylhä's brilliant and sharp comments also gave me to go the right direction toward to my goal effectively.

List of Tables and figures

Table 1: The change (%) in the population over 65 years of age during the years 2000-2012

Table 2: The frequency distribution of decedents among three age groups and genders

Table 3: The frequency distribution of the deceased with dementia at the place of death during 1998-2013

Table 4: The percentages of death place along with age of deceased and gender in the study period.

Table 5: The associations of death place, age, gender, and the death year for people with dementia. Odds ratios (ORs) and 95% confidence intervals with binary logistic regression models

Fig. 1: Age-standardized dementia mortality including Alzheimer's disease in 1971 to 2014 in Finland

Fig. 2: The percentages of deceased people with dementia among age groups separated by genders during the years 1998-2013

Fig. 3: The death place of people with dementia during the years 1998-2013

Fig. 4a: The place of death during 1998-2013 by age group 70-79

Fig. 4b: The place of death during 1998-2013 by age group 80-89

Fig. 4c: The place of death during 1998-2013 by age group 90+

List of Abbreviations

EOL=End of Life

LTC=Long Term Care

NH= nursing home

POD=Place of Death

THL=the National Institute for Health and Welfare (formerly the National Research and Development Centre for Welfare and Health STAKES)

Chapter 1: Introduction

1.1 Background: The importance of studying the place of death for people with dementia

Dementia is the most prominent disease among older population associated with a loss of independent function and autonomy, which affects not only the patients but also their family members. Age is the greatest risk factor for dementia and thus dementia is the one of the most common cause of death among the older population. (Seshadri et al., 1997, Herbert et al., 2001) The prevalence of dementia has been drastically expanding among the developed countries (Brayne et al., 2006, Wu et al., 2014). In particular, the prevalence of dementia among the oldest age group (over 85 years old) is expected to expand over the world dramatically (Alzheimer's association, 2013).

The global population structure has changed over the world since the early 21st century. It is mainly attributed to the longer life expectancy and quickly advancing technical improvements in many areas of health related fields including medical treatments or therapies (Alzheimer's association, 2013). The substantial gain in life expectancy and low fertility in western European countries, the USA, Canada, Australia, New Zealand, and Japan significantly increased the proportion of those aged 65 and older among the whole population (Christensen et al., 2009, Rechel et al., 2013). Being educated to persuade a better quality of daily life contributed to this change as well. Hence, the enlarging older population among the total population is a worldwide phenomenon, especially during the last two decades.

Among EU countries, Finland is growing old most rapidly. By 2050 more than a quarter of the population in 5.4 million will be over 65year olds (Official Statics Finland, 2013) as shown in Table 1 and the proportion of 80 years and older among the total population will be close to 8% based on the OECD estimation (OECD, 2012). According to this, the death caused by or with dementia including Alzheimer's disease dramatically increased during the last decade, nearly doubling, from 8% of total deaths to 15% (Official Statistics Finland, 2013).

Table 1: Change (%) in the population over 65 years of age during the years 2000-2012

Country	65+ in total population (%)			80+ in total population (%)		
	2000	2011	2050	2000	2011	2050
Finland	14.9	17.8	27.1	3.4	4.8	10.2
Japan	17.4	23.3	35.7	3.8	6.7	13.9
USA	12.4	13.3	20.6	3.3	3.7	8.0

Calculation from data: OECD 2012: www.oecd.org/dataoecd/52/31/38/23085.xls

Japan is the leading country with the highest proportion of older population among the total population as shown in Table 1. In 2011, almost one-quarter of a total population of 127 million was over 65 years old, and the ratio is expected to rise to nearly 40% by 2050, even though the total population is anticipated to decline as much as 30% to around 87 million by 2060 (McCurry, 2015). Hence, the number of older population with dementia in Japan will increase to 37 million by 2035 (Iwatsubo et al., 2006, Dodge et al., 2012).

At present, the USA had a smaller share of the older population in a total population of 304 million than many other developed countries as shown in Table 1, as more elderly population constituted only one-eighth (12.8%) of the entire population in 2009. Even though the slower increasing rate in the older population compared with other developed countries, the proportion of the older adults in the USA is estimated to reach up to 20% of the total population by 2050 due to a still growing population (OECD, 2012). A large number of the older population compared with other countries has a serious influence in the society. Currently, 41.4 million of the total population in the USA is already over 65 years old. Additionally, among the older population, the oldest old group (aged over 85years) has been the most rapidly growing age group last decade in the USA (Corrada et al., 2010). Presently, Alzheimer's disease was the 6th leading cause of death for those age over 65 years in the USA in 2010 (Alzheimer's association, 2013). However, the Alzheimer's Association Report published in 2014 anticipated that more than 5.2

million of US Americans have dementia including Alzheimer's disease, and the number is projected to reach 7.1 million by 2025 due to the baby boomer generation (Alzheimer's association, 2013, Plassman et al., 2007). Near the future, the prevalence of dementia may increase largely in the total population. It may prompt the larger proportion of death related dementia.

In the EU, the number of people with dementia is predicted to more than double to 14 million between 2010 and 2050, which is equal to 3.3 % of the total population and 10.1% of the population aged over 65 years (Mura et al., 2010, Rechel et al., 2013). In England, 15% of all deaths between 2001 and 2009 were related to Alzheimer's disease, dementia or senility (Badrakalmuthu and Barclay, 2014). A study of the place of death of people with dementia in five European countries presented that the proportion of death related to dementia was 4.6% among the total death of individuals aged over 65 years in Belgium, the Netherlands, England, Wales, and Scotland in 2003. However, in this study, the researchers notified the underestimation of the death number caused by dementia. (Houttekier et al., 2010).

Furthermore, looking at the demographic facts in the developing countries, rapid increases in the numbers and proportions of the older population are predicted for China, India, and Latin America as well. Hence, by 2050, the number of the older population in the world is predicted to reach up to 1.25 billion, which accounts for 22% of the world's population. (Prince et al., 2013). It would be anticipated the prevalence of dementia might increase in the developing countries as well. Hence, the increasing prevalence of dementia will have a significant impact on the society over the world, especially since there is currently no cure available for this disease.

End-of-life (EOL) care may refer to support for people who are in the last few months or years of their life. On this viewpoint, EOL care, especially for people with dementia, should help people to live comfortably or painlessly toward to the death as well as die with dignity. Therefore, it is important how and where care is organized to provide the comfort support to people with dementia at the end of life. Additionally, it may include the palliative care, specialized medical care for people with serious illness, to help to continue with daily life and improve the quality of life.

Previous those studies of EOL care conditions illustrated the current care situations of EOL care at home, in the hospital or the long-term care (LTC) facility. The researchers in those studies pointed out many issues related the EOL care and suggested searching for using different care services. It is the quality of care toward and at the EOL stage that needs to be improved for the benefits of not only people with dementia but also their caregivers. Studying the place of death for the people with dementia describes the care service use at the very end of life. The place of death has a crucial role in organizing EOL care. Therefore, it is important to study the place of death.

1.2 Dementia

Dementia is defined as a decline in memory or cognitive performances severe enough to reduce a person's ability to accomplish everyday activities, possibly over a long period (Alzheimer's association, 2013). As shown in attached Appendix 1, nearly 80% of the symptoms of dementia are caused by Alzheimer's disease, including vascular dementia, dementia with Lewy bodies (DLB), and frontotemporal lobar degeneration (FTLD), mixed dementia, Parkinson's disease (PD), Creutzfeldt-Jakob, and normal pressure hydrocephalus dementia. Physicians diagnose dementia according to the score of Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association 2013, Appendix II). The fifth edition of the DSM (DSM-5), which was released by the American Psychiatric Association in 2013, is internationally recognized and used by many professionals. Dementia is integrated into diagnostic categories of major and mild neurocognitive disorders in the DSM-5 (American Psychiatric Association 2013). According to this definition, damaged nerve cells (called neurons) in the brain cause dementia symptoms. Damaged neurons are not able to keep normal function and may die, which causes a decline in memory, a loss of ability to think clearly, or a change of behavior. Eventually, dementia symptoms affect bodily functions such as walking, standing up straight and swallowing. Severe stages of advanced dementia may require bedridden and around-the-clock care. Treatment of dementia depends on its cause. However, in most progressive types of dementia, including Alzheimer's disease, there is, unfortunately, no cure for dementia currently (Alzheimer's association, 2013).

The prevalence of dementia has been reported increase exponentially from age 65 to 85, and particularly after age 90, doubling every five years (Jorm and Jolley, 1998, Corrada et al., 2008, 2010). Brayne et al. (2006) reported a robust increasing tendency of dementia among the population in the UK last decades; 6% of the group aged 65-69 years and 58% of the people aged over 95 years died with dementia. It was also noted that the number of individuals who have dementia among women is higher than that of men (Herbert et al., 2013). The higher occurrence of dementia among women is essentially explained by the fact that women's longer life expectancy compared with the men's life expectancy. However, no significant difference in the age-specific incidence of Alzheimer's disease or any other type of dementia between men and women is found in studies (Herbert et al., 2001, Fitzpatrick et al., 2004, Kukull et al., 2002, Evans et al., 2003, Barnes et al., 2003, Fillenbaum et al., 1998).

During the process of dementia, the symptom accelerates the behavioral disorders or confusions such as disorientation, restlessness, aggressiveness or violent behavior. Symptoms of dementia get worse slowly over a long period. In the most cases it takes over eight to ten years until the death. Compared with other terminal diseases such as cancer, the duration of the terminal phase of dementia usually lasts longer than six months and may even last for years. (Mitchell et al., 2009). Because of this long and slow process of the symptom, people with dementia are categorized as a specific group in the EOL care. The extended period of both physical and cognitive deterioration may require special health and social care services, such as institutional LTC (Aguero-Torres et al., 2001). Hence, the increasing number of cases is crucially affecting government budget at social and health care expenditure on LTC in many countries (Knapp et al., 2007, Wimo et al., 2013). It causes serious problems in the practice of social and health care such as resulting in lack of sufficient professional care for all patients (Knapp et al., 2007).

The prevalence of dementia has been drastically expanding among the developed countries (Brayne et al., 2006, Wu et al., 2014). In particular, the prevalence of dementia among the oldest age group (aged over 85 years) is expected to expand over the world dramatically (Alzheimer's association, 2013). Shortly, this rapid and considerable increase in dementia may cause important social and economic consequences all over the world. (Ferri et al., 2005, Kukull, 2006, Knapp et al., 2007, Prince et al., 2013, Wimo et al., 2013).

1.3 Care at the end of life for people with dementia

In practice, the majority of people with dementia live at the residential home in the community, and informal caregivers such as family members, relatives or friends provide mostly their daily care (Alzheimer's association, 2013). The long duration of the caregiving may burden a caregiver's personal health and life, leading to the early admission of the person with dementia to an LTC facility or hospital (Jagger et al., 2000, Sachs et al., 2004, Mitchell et al., 2009, van der Steen, 2010). The advanced stage of dementia mainly requires more intensive care, which may eventually induce an institutional care facility entrance (Gaugler et al., 2007, Etters et al., 2008). However, the situation in LTC facilities and in hospitals is questionable, as the quality of care may be inadequate in many respects, such as aggressive or poor medical treatments, restricting the autonomy of people with dementia, isolating patients from society or family and relatives, or using the methods of body restraint (Volicer, 2005, Falk, 2013). EOL care transitions, particularly from LTC facilities to hospitals are common, and those transitions may become a burden to people with dementia (Lamberg et al., 2005, Gozalo et al., 2011, Houttekier et al., 2014, Nihtila and Martikainen, 2007).

Among the EOL care for people with dementia studies that are focusing on how the quality of care provided for the clients toward to and at the EOL, have increased. (Volicer, 2005, van der Steen et al., 2010, Pinzon et al., 2013, Badrakalmuthu and Barclay, 2014, Stewart-Archer et al., 2015). Nowadays, the LTC evaluation and research concentrate the process based on the outcomes of care delivery, which means how care affects people with dementia toward and at the EOL (Stewart-Archer et al., 2015). Currently, social and health care systems vary in different countries (Morrissey et al., 2015). Each country has been reforming the system according to its own national social and economic status; for example, the health and social care system reform based on the change of the population situation in the USA (Halpern, 2015). Similarly, the reform based on the population structure change was done in England (Marshall, 2015), in Germany (Stock, 2015), in Sweden (Anell, 2016), in Netherland (van Ginneken, 2016) and Canada (Lewis, 2015). Their goal is the same, to improve the health care system to adjust to this growing phenomenon, and to support people with dementia and their families.

EOL care for people with advanced dementia involves many issues: suitable symptoms' management including pain and behaviors, involvement in programs such as the hospice or palliative care, and making decisions about medical treatments (Volicer, 2005), accepting the death of people with dementia by themselves or by the caregivers closed to them, offering the care focused on their comfort, the presence of family at the EOL, people's appearance at the EOL, and keeping and admiring the preference of religious desire or solitude, and the time "to be with God" of people (Stewart-Archer et al., 2014), the necessity of skilled nurse caring or person-centered nursing care (van Zadelhoff et al., 2011), or understandable, smooth communication between caregivers or family and people with dementia, the well-being of people with dementia, no tube feeding (Friedrich, 2013), and the care in a dedicated dementia unit (Engel et al., 2006).

When the symptoms worsen during the EOL period, the following serious issues need to be considered and understood to improve the care.

1. The period of EOL of progressive dementia is long and unpredictable

Compared with other serious terminal illnesses such as cancer, during which the EOL stage usually lasts about six months, the duration of the EOL stage of progressive dementia may last much longer; i.e. up to several years, (Alzheimer's association, 2013). Anticipating the length of this final stage is difficult. This unpredictable uncertainty is a significant burden and may cause depression in patients and their caregivers.

2. The communication distraction

The last severe phase of dementia causes the interruption of communication and disturbances in showing feelings, thinking, or asking for help (Mitchell et al., 2009). In such cases, even close family and friends or professional caregivers may misunderstand the patients. Judging or conjecturing the need or thinking of people with dementia may confuse them and result in a wrong direction of care. This late stage may accompany by a high risk of improper care and may cause frustration on both sides.

3. Decision-making in the activities of daily life (ADLs) and medical or life-prolonging treatments

Once the symptoms progress, people with dementia cannot easily express their desires. At this stage, it is important to agree on a guardian who will make decisions on behalf of the patient. Having and discussing the advance directive well before the progress of the symptom between the patient, family, and medical care professionals have legally ratified in many developed countries including the USA and Canada (Alzheimer's association, 2013). As a result, this would avoid the poor situation at the EOL care such as, medical professional staff may give aggressive treatments such as permanent enteral tube nutrition, PEG, antibiotics, painkillers, morphine, intravenous fluid for rehydration, psychotropic drugs, or antidepressant drugs (Kovach et al., 1999, Givens et al., 2010, McCann et al., 1994, Zweig, 1997). On the other hand, sometimes people with severe dementia may be undertreated, and the terminal phase of symptoms is seen as a part of the process of natural death (Harris, 2007). A certain concept of dignified death does not exist in many countries.

4. The recognition of dementia as a terminal illness

Dementia is a terminal illness; however, this is often not recognized or accepted by family members and informal caregivers. Sometimes family members or relatives do not agree the patient is moving toward the EOL stage. They request a cure for the patient or aggressive treatment, even though it may cause severe pain or suffering for the patient. (Chang and Walter, 2010, Sachs et al., 2004). EOL care should be focused on maintaining a calm and comfortable daily life for the patients rather than vigorous treatment. Unfortunately, informal caregivers lack sufficient knowledge about palliative care (Hurley et al., 2000, Meeussen et al., 2012, Sampson et al., 2006, Bayer, 2006). Therefore, there is a great need for policy reforms in the social and health care system. At least, clear and supportive policy should be established at the same level of care and support systems during the terminal phase of cancer.

The best EOL care for people with dementia near the death should focus on to maximizing their comfort in the daily life. The majority of family members desire the comfort as the primary goal of care for their relatives with advanced dementia (Mitchell et al., 2009). Person-centered care for people with dementia was introduced by Tom Kitwood and others in England (Kitwood, 1997a, 1997b; Kitwood, 1988). This concept defined people with dementia as concealed rather than lost. Even though his/her

bodily functions have declined, the patient can still recognize whether or not someone is paying attention to him/her. Since person-centered care concepts introduced the EOL care for people with dementia has developed into aiming at the well-being of individual rather than cure them (Verbeek et al., 2009, Edvardsson et al., 2010, Koren, 2010). Since then, the autonomy, individualization, personhood and well-being of people with dementia are valued and emphasized on the care, which has been less concerned at LTC facilities (e.g. the use of restraints, aggressive medical treatments such as using antibiotics or feeding tubes). Together with this concept of person-centered care, the important effect of physical environment has been recognized and it was suggested that a small, home-like environment brings the normalization of daily life to people with dementia (Day et al., 2000, Calkins, 2001). The effectiveness of home-like care facility for people with dementia was investigated and increased the attentiveness and responsiveness for well-being of residents were reported (van Zadelhoff et al., 2011). Currently, the similar concepts vary in countries such as referred as group living in the Netherlands, Belgium and Sweden, group homes in Japan, and residential groups in Germany (Verbeek et al., 2009).

The other point should be noted at the LTC. It seems that the policy of many developed countries has changed toward to delay entering into the LTC facilities by enabling people with dementia to remain at home for as long as possible (Moise et al., 2004, Verbeek et al., 2012).

1.4 Place of death

The place of death and changes in place of care before death has been studied as quality indicators for EOL care and there are significant differences between the countries (Perrels et al., 2014, Badrakalmuthu and Barclay, 2014, Houttekier et al., 2010). Houttekier et al. (2011) noted that studying the death place of people with dementia can provide essential information for the planning of EOL care services and facilities, because they are more likely to enter institutional care. The studying of the death place of people with dementia among the EU countries provides visions that would

help to develop the better policies to attain the ideal EOL care for the people with dementia (Houttekier et al. 2010).

There have been changes in the places of death of people with dementia in several countries. In Belgium, the place of death shifted from hospitals to residential care homes between 1998 and 2007 among the older population (aged over 65 years) (Houttekier et al., 2010). Additionally, the feature of people with dementia at the end of life was studied using the Belgian Network of General Practitioners (GPs), which has a long history in the surveillance of health-related epidemiological data and EOL issues. In this study, people with dementia died in a care home (59%) more than people without dementia (19%). Further, 74 % of the people with dementia received palliative treatment in 2008. Old people (56% was aged over 85 years), and more often female (66%) died with dementia among this population, and their deaths were more frequently non-sudden compared with the death of people without dementia in this study. (Meeussen et al., 2012).

In the UK population-based prospective study, of the oldest old (aged over 85 year) who were community dwelling a year before death, a majority had cognitive impairment (one-quarter had mild/moderate, one-third had severe). Those oldest old most frequently died at the acute hospital. Just only 8% died in the community. (Perrels et al., 2014). The ratio of dying in hospital of people with dementia in the UK used to be one of the highest proportions in Europe in 2003 (Houttekier et al., 2010). However, this trend towards hospital death in dementia reversed during last decade (2001-2010). The hospital deaths started to decrease in 2006 and residential care home deaths had been increasing (0.60% per year) due to the growing of care home bed provision. (Sleeman et al., 2014). In the USA, among a cohort of Medicare beneficiaries with dementia, home deaths increased from 19.9% in 2000 to 22.8% in 2009 (Teno et al., 2013).

Residential care facility (LTC facility, care home, nursing home) was the most frequent place of death for people with dementia in Belgium, Netherland, England, Wales, Scotland, Czech Republic, New Zealand, the USA, and Canada. However, majority people with dementia died at a hospital in South Korea and Hungary. In Italy, Spain and Mexico people with dementia died at home. Death at palliative care institution

was very rare in all countries except the USA (but still only 2.9% in 2005). (Reyniers et al., 2015).

Even though when dementia severely progress still most people favor living at home as long as possible since this is a familiar environment (Tucker, 2008). Nevertheless, the long progression period and misbehaving achievement, the difficulty of communication, and disability of conducting daily life performance enforce them to enter the institutional setting or hospital wards (Mitchell et al., 2004, Mitchell, 2005, Lamberg et al., 2005). Once the symptom progressed people with dementia cannot live at home safely due to the severity of cognitive and functional disability for daily life (Agüero-Torres et al., 2001, Verbeek et al., 2012, Alzheimer's association, 2013). Alongside of research for constructing better care systems, in many countries, care setting has been changed from the traditional institution to home-like setting at nursing care facilities. Those are now defined as the last residential place till death for them (Verbeek et al., 2009, van Zadelhoff et al., 2011, Knapp, 2007, Aaltonen et al., 2014).

With the progress of symptoms, the people with dementia move into the LTC facility but at the end of life they may be transferred to the hospital. This is the other issue related to EOL care for people with dementia should be discussed. This transition is defined as the EOL care transitions, such as moves from the nursing home or residential care facilities to the hospital, or community dwelling to the hospital or residential care facility during the last few months of the life. Those transitions are quite common, even though they may be burdensome for people with dementia. These transitions may cause emotional distress and agitation to people with dementia at unfamiliar circumstances (Naylor et al., 2005, Callahan et al., 2012, Gozalo et al., 2011) and raise the risk of medical errors such as administering the wrong intravenous antibiotics in the hospital or unnecessary treatments (Meier and Beresfors, 2008, Coleman et al., 2003, Naylor et al., 2004).

In the USA, between 2000 and 2007 among nursing home residents with dementia a fifth of the people with advanced dementia (90,228 out of 474,829 who were older than 66 years) experienced at least one transition during their last three months (Gozalo et al., 2011). The majority of hospitalizations among the nursing home residents with advanced dementia were caused by infections (Givens et al., 2012). However,

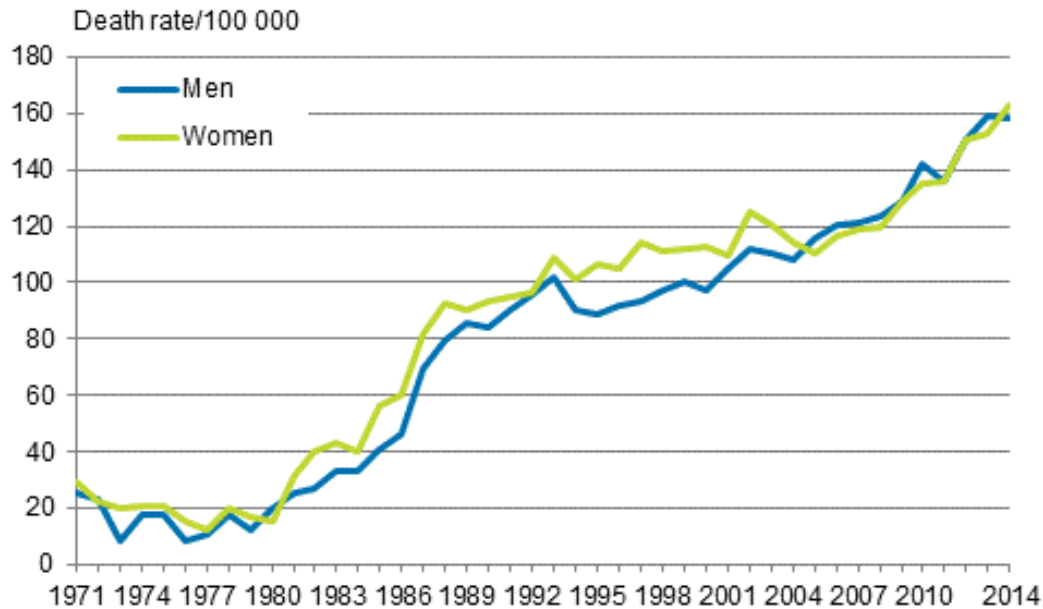
Gozalo et al. (2011) noted transitions among people with the advanced stage of dementia at the end of life increases confusion because of unfamiliar settings and providers, lack of communication, poor ability to address the patient's special need such as assistance with feeding. Even though the condition such as pneumonia, urinary tract infection, or dehydration prompting the hospitalization, but those could easily be treated in a properly equipped and staffed nursing home.

1.5 Dementia trend in Finland

In 2014, the most common cause of the death category for older people in Finland was the circulatory system and neoplasms, and dementia followed them. Among the older population, nearly one-fifth of those aged 65 and older and one-third of those aged 95 and older died of dementia. As stated by Eurostat's statistics in 2012, Finland had the largest dementia mortality of men and women about the population in EU countries. (Official Statistics Finland, 2015). In 2011, every fifth of over 80 years died of dementia. One in five deaths among women and one in ten among men were affected by dementia as shown in Fig. 1. (Official Statistics Finland, 2015a). Since 1996 Finland has used ICD10, the International Classification of Diseases, but in 2005 changed to adopt the WHO guideline that limits the use of pneumonia as an underlying cause of death. Currently, the Causes of Death Register in Finland considers the cause of death as dementia if a person has both pneumonia and dementia. It might affect the increase in dementia as the primary cause of death. (Official Statistics Finland, 2013). Along with the increased prevalence of dementia, health, and social service use have been growing. Nihtilä et al. (2008) reported that dementia was one of the strongest predictors of institutionalization in the population-based 6-year follow-up study. 70% of women and 55% of men with dementia were institutionalized. Voutilainen et al. (2007) found that 95% of the residents of long-term institutional care facilities and 60% of the clients of home care have some dementia symptoms.

Fig. 1: Age-standardized dementia mortality including Alzheimer's disease) 1971 to 2014

(Source: Causes of death, Statistics Finland 2015)



1.6 Health and social care services in Finland

Finland, the same as other Nordic countries and UK, offers universal coverage for a wide-ranging variety of health and social services. As of 2015, 317 municipalities (median size is fewer than 6,000 inhabitants) provide health and social services to their residents in Finland. Small or middle size municipalities may participate together with other municipalities or may purchase services from NGOs, private companies, or other municipalities. (Häkkinen, 2005, Teperi et al., 2009, Vuorenkoski, 2008). At the funding structure, the Finnish system is more decentralized and mixed than other Nordic countries (Teperi et al., 2009). Health and social services are funded mainly by taxes, and partly by user fees. Public primary health care is provided by municipal health centers (the same as primary care hospital in the other countries), which offer both outpatient and inpatient care. A great proportion of older people is receiving the LTC in the health center. Finland is divided into 20 hospital districts and every municipality is

allocated to one hospital district. The central hospital at each hospital district offers specialized care to the district residents. There are other public and private hospitals in each hospital district according to the size of the region. There are five university hospitals in the country's largest cities. (Vuorenkoski, 2008). The municipalities have the responsibility of institutional LTC including nursing homes and other residential care facilities such as sheltered housing with 24-hour assistance, which provides the social and health care services. The municipalities also purchase the service from the for-profit and not-for-profit facilities. Finland is one of the first countries which has recognized the value of informal caregivers' participation as the allowance by the Family Carers Act ('Omaishoidon laki 937/2.12.2005 – came into force on 1.1.2006). Older people who live in their home can have a formal home care delivery and be able to use the short-term respite care at LTC facilities in Finland. (Vuorenkoski, 2008, Häkkinen, 2005).

One of the primary goals of Health and Social care in Finnish policies is helping old people to stay at home or in a home-like environment as long as possible. The National Framework for High-Quality Services for Older People sets quantitative targets, which goals only 3% of over 75 years' population are in a LTC institutional facility or in a primary care hospital (health center)'s ward. These goals are supported by formal home care delivery at home including preventive and rehabilitative services. Nursing homes and sheltered housing with 24-hour assistance are also available to people who can no longer manage to live at home. (Ministry of Social Affairs and Health, 2008). Official Statistics Finland (2013) showed that the numbers of older people in LTC facility have been falling. By the end of 2012, the number of older people in residential homes totaled 13,587, showing a decrease of 12.5 %, and in a primary care hospital, it dropped by around 13 % in the previous year. On the contrary, the number of old people in sheltered housing with 24-hour assistance increased by 4.7%, totaling 32,257. The average age of old people in residential homes and sheltered housing with 24-hour assistance was 83.5 years, of which women accounted for 71.7 %.

The structure of the social and health service delivery in Finland changed last decade from institutional care to outpatient LTC. Nihtila and Martikainen, (2007) stated that the Finnish government has started to study the efficiency of institutional care for people with dementia with this reform, It is focusing and analyzing the future need for institutional care from the viewpoint of the relationship between the increasing numbers

of older people and socio-economic factors and housing conditions. National Dementia Strategies (2012-2020) state the significance of the well-being and the quality of life of people with dementia.

In Finland, a quarter of decedents who were over 70 years old had dementia in 2002-2003. The community dwelling people with dementia had care transitions more than those without dementia two years before death. Additionally, at the very end of life people with dementia moved more often between care facilities and hospitals than people without dementia. (Aaltonen et al., 2012). Furthermore, the higher frequency of transitions was reported on the sheltered housing with 24-hour assistance (Aaltonen et al., 2014). This higher frequency of transitions may cause the negative impacts the same as Gozalo et al. (2011) noted. Nearly 10% of the decedents of people with advanced dementia at care facilities between 2002 and 2008 had potentially burdensome care transitions such as multiple hospitalizations during the last three months of life in Finland, even though the number of transitions during this period decreased. Interestingly, the transitions were the most common in sheltered housing, especially in the last three days of life. However, compared with in the USA, the frequency of burdensome transitions were less frequent in Finland. (Aaltonen et al., 2014). Care for older people in Finland strongly guided to avoid unnecessary care transitions. The shifting toward home-like care facility such as sheltered housing with 24-hour assistance from the traditional nursing home is rapidly progressing in Finland.

Nevertheless, despite this wealth of research, the details of the place of death for the old people with dementia and the end-of-life care for the elderly people with dementia in Finland have not been reported on yet.

Chapter 2: Aims and Research questions

Finland is growing old most rapidly among EU countries. The structure of the social and health services changed last decade from institutional care to outpatient long-term care with the rapid expansion of the older population and the frequency of dementia. The aim of this study was to reveal the trend in the place of death of people with dementia in Finland.

Research questions are;

- 1) What are the places of death among people with dementia?
- 2) How the places of death differ between the different age group of 70-79, 80-89, and 90+, and between men and women?
- 3) How has the frequency of the places of death have changed between the years 1998 and 2013?

Chapter 3: Data and Methods

3. 1 Data sources: registers

The dataset was derived from Finnish national health and social care registers (the National Institute for Health and Welfare, THL) and the Causes of Death Register (Statistic Finland). The Causes of Death register include information on the date of death and all causes of death as stated on each individual's death certificate. The information provided was age, gender, and the cause of death. Immediate, underlying, intermediate and contributing causes of death are used as the causes of death.

The information on care use at health centers, general hospitals, and university hospitals was taken from The Care Register for Health Care and The Care Register for Social Welfare, maintained by The National Institute for Health and Welfare (THL, formerly the National Research and Development Centre for Welfare and Health STAKES). The use of nursing homes and sheltered housing with 24-hours assistance were in The Care Register for Social Welfare. In Finland, the sheltered housing with 24-hour assistance is classified as housing services or community care, not as institutional care services.

The Finnish Care Registers linked with the unique Personal Identity Codes (PIC), which maintain unchanged throughout individuals' lives. Linking was done in Statistics Finland.

Diagnosis information included both the main and secondary diagnoses were taken from The Finnish Care Registers and immediate, underlying, intermediate and contributing the causes of death from the Causes of Death Register. People would be identified as having dementia if they had International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Version for 2010 codes F00-F03, or G30 (Alzheimer's disease) (WHO 2013). In brief descriptions of diagnosis criteria for the dementia of ICD -10 done by WHO were F00 (Dementia in Alzheimer's disease), F01 (Vascular dementia), F02 (Dementia in other diseases classified elsewhere), F03 (Unspecified dementia) and G30 (Alzheimer's disease).

3.2 Study population

The data population was constructed by the statistics researcher at School of Health Sciences and Gerontology Research Center, the University of Tampere.

The study population was identified by Statistics Finland. The data were collected in four different sets and included in the information on people who died at the age of 70 or older in the study years from 1998 to 2013 and the care use they received two years (730 days) before death. The data set in total (N=502656) consisted of information on all those who died in the year 1998, and 2002-2013, and a 40% random sample of the years 1999-2001.

People with dementia were identified from the Causes of Death and from the care registers with the ICD-10.

Permission to access register data was obtained from each register controller. As a part of the COCTEL research group at University of Tampere, Health Science, Gerontology group, the author had the permission to use the data for this study from Statistic Finland and THL. The linking of data was done in Statistic Finland, thus the author had no access to PICs. The research plan was approved by the Ethics Committee of the Pirkanmaa Hospital District.

3.3 Methods

Data were analyzed using IBM SPSS statistics Windows version 22 (IBM Corp., Armonk, N.Y., USA).

The analysis procedures were

1. Description of the sample
2. Cross-tabulations with the outcome variable POD
3. Regression analysis to reveal the effect of year of death, gender and age.

All variables used in the study coded categorically.

Outcome (dependent) variable:

Place of death: 1= home (including care sites that offer non-round-the clock care),
 2= specialized care hospitals (including private, district, general and university hospitals),
 3 = primary care hospital (called as health center in Finland),
 4= nursing home,
 5 = sheltered housing with 24-hour assistance.

Independent covariates:

1. Gender: 1=man, 2=woman,
2. Age at the death divided into three groups 70-79, 80-89, and 90+,
3. Year of death from 1998 to 2013.

First, the study population and how the age and gender distribution has changed between the years 1998 and 2013 were described. Then, the frequency of different places of death and how they vary according to age at the time of death and gender was analyzed with cross-tabulations. The association of the place of death with age, gender, and the year of death were analyzed with logistic regression analysis. Binary logistic regression models were used and showed as odds ratios (ORs) and 95% confidence intervals. Statistically significant odds ratios are marked with the *, which had significant at $p < 0.05$. The years 2001-2003 were used as a reference for the sheltered housing with 24-hour assistance. The sheltered housing with 24-hour assistance could be identified from the registers 2002 onwards. Due to this, the data of sheltered housing with 24-h assistance was mainly used from 2001 to 2013 for the analysis. University hospital and general hospital were combined under the category of the specialized care hospital. Health center, the same as primary care hospital in other countries, the nursing home and the sheltered housing with 24-hour assistance were calculated separately. The models were adjusted for other major diagnoses drawn from the care registers and causes of death register, including cancer, diabetes, psychosis, depressive syndromes or other mental health disorders, Parkinson disease or other neurological diseases, chronic asthma and chronic obstructive pulmonary disease or other respiratory diseases, arthritis or osteoarthritis, the hip fracture, stroke, ischemic and other heart disease excluding rheumatic and alcoholic diseases, and other diseases of the circulatory system.

Chapter 4: Results

Research questions were

- 1) What are the places of death in people with dementia?
- 2) How the places of death differ between the different age group of 70-79, 80-89, and 90+, and between men and women?
- 3) How the places of death have changed between the years 1998 and 2013?

Contents of this chapter are

4.1 Description of Study population

4.2 Place of death.

4.3 Differences between age groups, the gender, and the study period

4.4 Regression analysis of the association between the risk factors and place of death

4.1 Description of Study population

In this data set during 1998-2013, a total number of deceased was 520656, and the number of people who died with dementia totaled 140034 (27.9% of the total). Among the people with dementia the maximum age at the time of death was 111 years, and the minimum age 70, due to how this dataset was constructed. The data include individuals who lived in Finland and who died between 1 January 1998 and 31 December 2013 at the age of 70 or older. The mean age in death was 86.0 years and increased during the study period from 85.4 years in 1998-2000 to 87.0 years in 2013. Women dominated the study group with 67.4% (Number =94,345) (Table 2). The mean age among women was 87.2 years, the maximum age 111 years, and among men the mean age in death was 84.0 years, the maximum age 109 years.

For further analysis, data were divided into three age groups (1=70-79, 2=80-89, 3=90+), based on the age at the time of death. The age group of 80-89 was the largest (52.4%, N=73,414), followed by the age group of over 90 (90+) (31.7%, N=44,450) and the age group of 70-79 (15.8%, N=22170).

During the whole study period (1998-2013), 27.9% of the people aged 70 or older died with dementia in Finland (Table 2). Dying with dementia increased between the study years: the proportion of those with dementia increased between the study periods from 22% to 33.9% (Table 2).

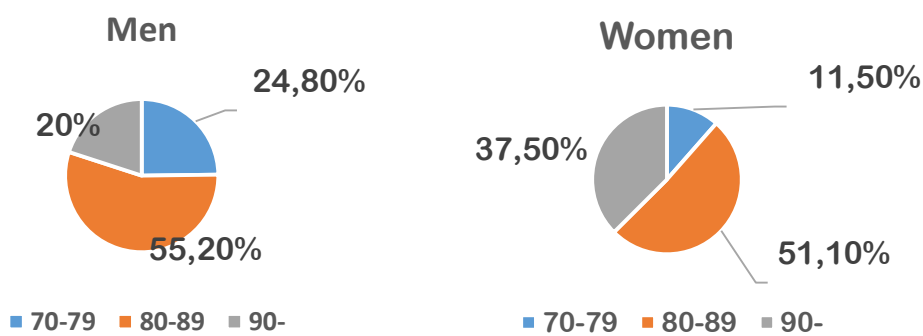
Table 2: The frequency distribution of decedents among three age groups and genders

	1998-2000	2001-2003	2004-2006	2007-2009	2010-2012	2013	Total
N with dementia	13617	20615	26537	30935	35429	12901	140034
% of the total number of 70+ deaths	22.0	24.5	26.3	29.3	31.6	33.9	27.9
Age, mean	85.4	85.6	85.8	86.2	86.7	87.0	86.0
Age group (%)							
70-79	18.9	18.9	19.9	15.2	12.9	12.9	15.8
80-89	54.0	51.4	51.4	53.5	52.8	51.0	52.4
90+	27.1	29.7	30.7	31.3	34.2	36.1	31.7
Age group men, %							
70-79	28.2	29.7	28.8	24.3	20.6	19.8	24.8
80-89	54.6	51.0	52.1	57.0	57.7	57.1	55.2
90+	17.2	19.3	19.2	18.7	21.7	23.1	20.0
Age group women, %							
70-79	14.9	14.2	12.7	10.7	9.0	9.2	11.5
80-89	53.7	51.5	51.1	51.7	50.4	47.7	51.1
90+	31.4	34.3	36.2	37.6	40.6	43.1	37.5

Comment: The majority (52.4%) belonged to the age group of 80-89-years-olds. Men with dementia N=45,689, Women with dementia N=94,345.

Even though the age group of 80-89-year-olds constituted the largest age group, the proportion of those who died at the age of 90 or older increased among both, men and women. This trend, people with dementia dying more frequently in later ages compared with the earlier study years, was seen in both genders. Dying at the age of 90+ was especially common among women; almost half of women with dementia died in their 90s in 2013 (43.1% of total women death in that year) (Figure 2). The percentages of dementia deaths in the age group of 70-79 decreased during the study period.

Fig. 2: The percentages of deceased people with dementia among age groups separated by gender in study period 1998-2013.



Comment: Dying in younger age was more common for men than for women.

4.2 Place of death

Primary care hospital (i.e. health center) was the most common place of death for the people with dementia in Finland: more than half of the people with dementia died at the primary care hospital during 1998-2013 (54.8%) as shown at Table 3. The second most common place was nursing home (21.9%). Adding specialized care hospital to the primary care hospital, 62.6% of the people with dementia died at the hospital. LTC

facilities including nursing home and sheltered housing with 24-hour assistance totaled 30.8%. In the whole study period, 8.9% died in the sheltered housing with 24-hour assistance. The proportion of home deaths in Finland was 6.3%, as shown at Table 3.

Table 3: Frequency distribution of the deceased with dementia at the place of death during 1998-2013

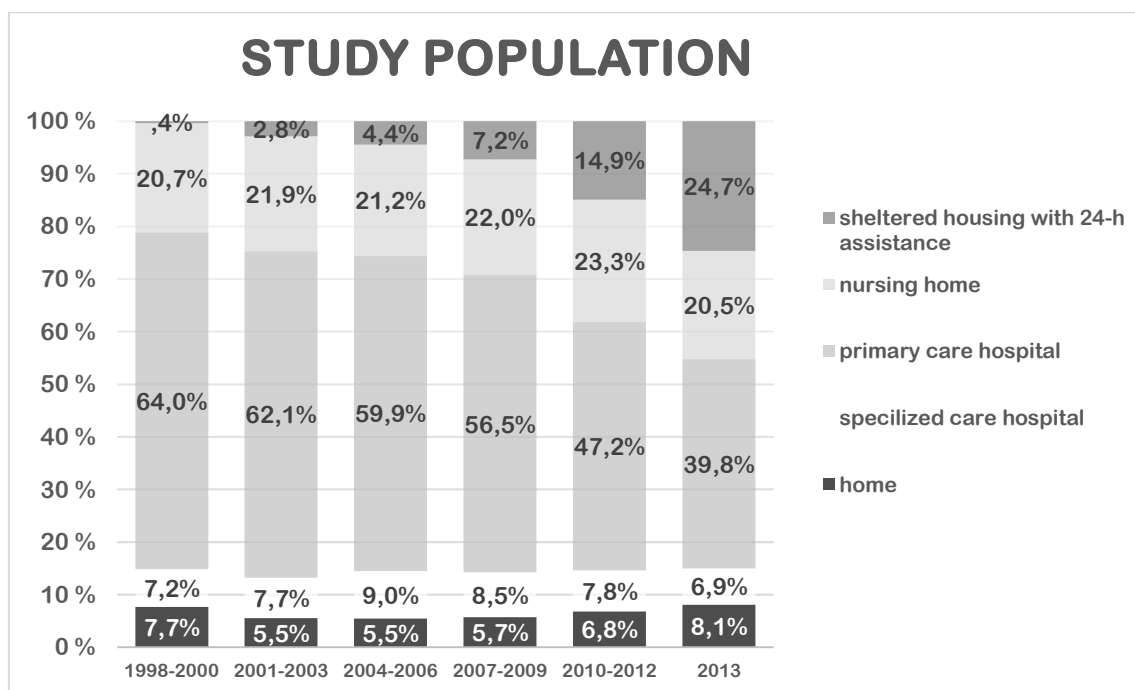
Place of death (%)	Home	Specialized care hospital	Primary care hospital	Nursing home	Sheltered housing with 24-h assistance
All	6.3	8.1	54.8	21.9	8.9
Age groups					
70-79	7.6	10.8	58.3	17.2	6.1
80-89	6.4	8.8	56.2	20.1	8.5
90-	5.6	5.4	50.8	27.1	11.0
Gender					
Men	7.2	11.5	56.6	17.6	7.1
Women	5.9	6.4	53.9	24.0	9.8

Comments: Primary care hospital (health center) is the most common place of death of people with dementia.

The proportion of those who died at home remained about the same during the period of 1998-2013: 7.7% in 1998 and 8.1% in 2013 (Figure 3). Among the hospitals, the primary care hospital was the most frequent place of death (54.8%) over the time, but the proportion decreased during the study years (from 64.0% in 1998-2000 to 39.8% in 2013). Death in the specialized hospital remained about the same during the study years (7.2% in 1998-2000, 6.9% in 2013). Death at LTC facility increased due to the increase

in deaths in the sheltered housing with 24-hour assistance. The proportion elevated dramatically and was eight times higher in 2013 (24.7%) than what it was in 2001-2003 (2.8%). The proportion of nursing home deaths did not change (20.7% in 1998-2000, 20.5% in 2013, and 21.9% in the entire period).

Fig. 3. Death place of people with dementia during 1998-2013



Comments:

1. Primary care hospital (health center) was the most frequent place of death in the all study years, but decreased during the study period.
2. Sheltered housing with 24-hour assistance increased during the study period.

4.3 Differences between age groups, the gender, and the study period

The mean age of death differs between the places of death. Younger people with dementia died at home (the mean age of 85.5 years, data not shown at Table)

or in the hospital (84.5 years in the specialized care hospitals and 85.8 years in the primary care hospital, data not shown at Table) compared with nursing home (87.3 years, data not shown at Table) and sheltered housing with 24-hour assistance (87.5 years, data not shown at Table).

Deaths in LTC facilities were more frequent in the oldest age group. Sheltered housing with 24-hour assistance was almost twice more frequent for those in the group 90+ (11.1%) than that for those in age group 70-79(6.1%) as shown at Table 3. Further, the oldest age group died in the nursing home (27.1%) more frequently than the younger groups (17.2% for 70-79, 20.1% for 80-89).

Women died in LTC facilities (50.2%, combined nursing home with sheltered housing with 24-hour assistance) more frequently than men (35.7%), while men died in the specialized care hospital (9.8%) or at home (9.2%) more frequently than women (5.3, 7.5, respectively) (Table 4). In 1998-2000, women died more frequently in the primary care hospital than men, but in 2013 the primary care hospital was the more common place of the death for men than for women.

The deaths in sheltered housing with 24-hour assistance increased enormous in all age groups during the study period (Fig. 4a; in the age group 70-79, 1.9% in 2001-2003 to 20.2% in 2013, Fig. 4b; age group 80-89 (2.9, 27.9 respectively) and Fig. 4c; age group 90+ (0.6, 27.9, respectively). This trend was seen in both genders, especially in men (2.0, 18.6 respectively). On the other hand, there was no change in the deaths at nursing home, except, among the age group 70-79: among them, it increased remotely (15.7% in 1998-2000 to 20.0% in 2010-2012, 18.1% in 2013). This trend was seen more among men (16.9, 17.1, respectively) than women (22.4, 22.3, respectively). Nursing home had slightly decreased in the older age groups but increased in the youngest.

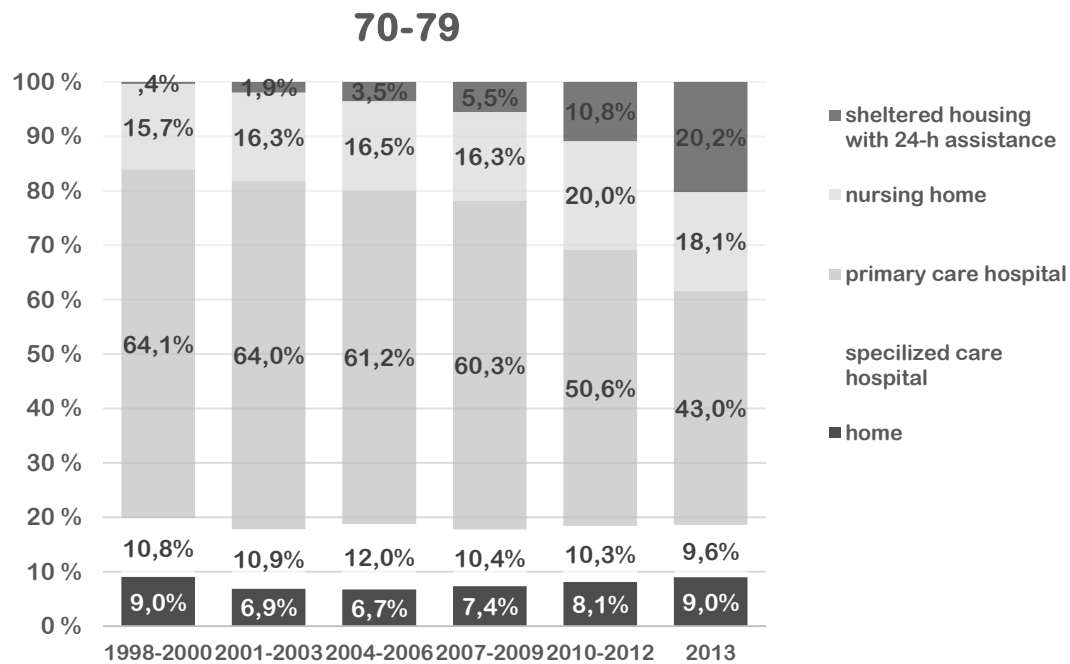
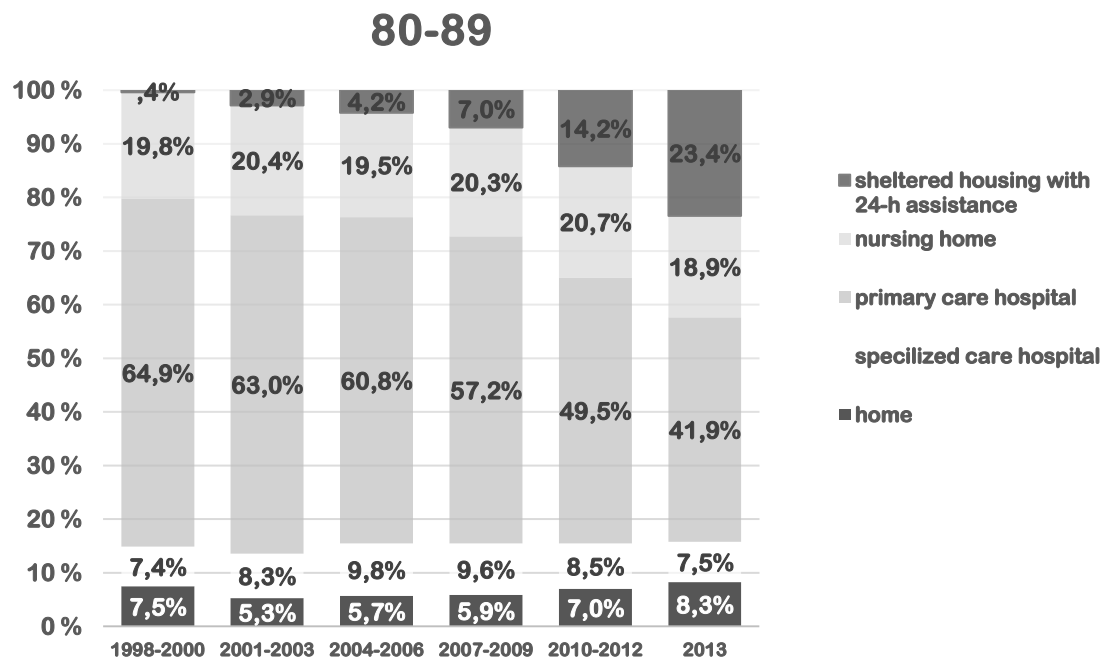
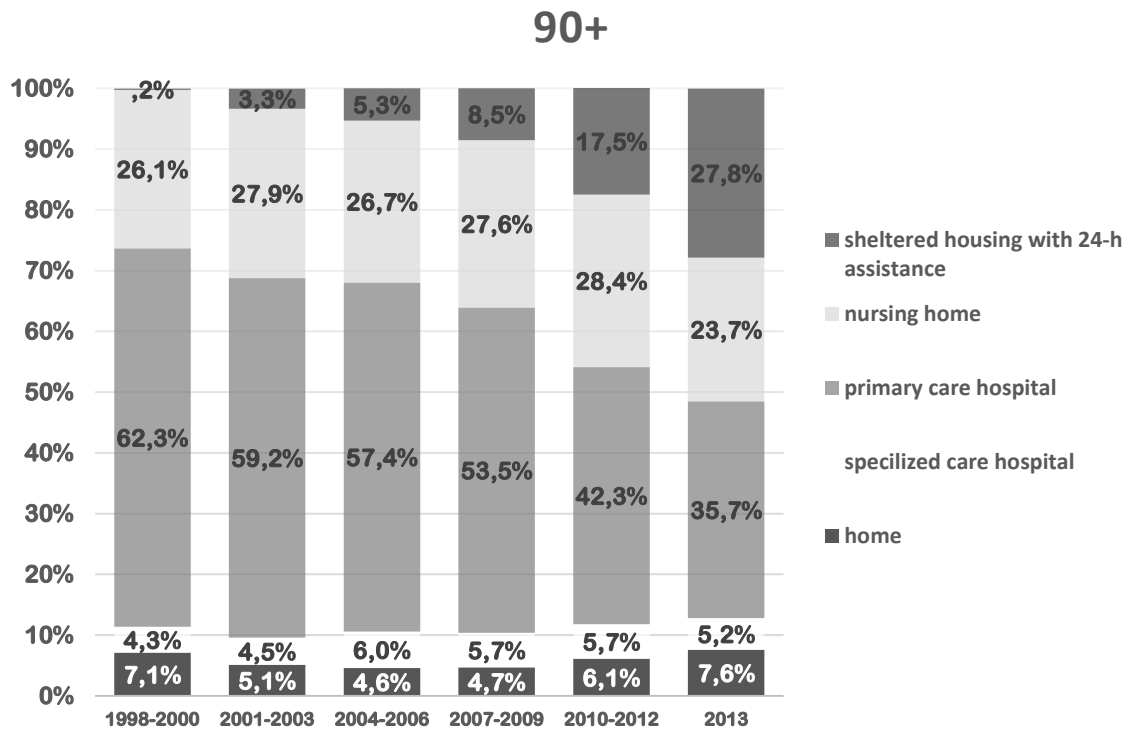
Fig. 4a: The place of death during 1998-2013 by age groups 70-79**Fig. 4b: The place of death during 1998-2013 by age groups 80-89**

Fig. 4c: The place of death during 1998-2013 by age groups 90+

There are some differences in the trend in the places of death of men and women (Table 4). The percentages of death at the hospital (general, university, and health center were combined) for men and women were decreased from 1998 to 2013, especially among women. In 2013, more than half of men with dementia died at the hospital (54.9%); nevertheless, women died less (42.2%). The frequency of nursing home deaths did not change for either men or women. However, deaths at sheltered housing with 24-hour assistance increased significantly, in particular for women (3.2% in 2001-2003 to 27.9% in 2013) compared with men (2.0%, 18.6%, respectively).

Home deaths among people with dementia were not very common (8.6% for men in 1998-2000, 7.2% for women during the same period) and remained the same in this period among either gender (9.2% for men in 2013 and 7.5% for women in 2013).

Table 4: The percentages of death place along with age of deceased and gender in the study period.

Place of death	gender	1998-2000 (%)	2013 (%)
Home	Men	8.6	9.2
	Women	7.2	7.5
Primary care hospital	Men	62.5	45.3
	Women	64.3	36.9
Specialized care hospital	Men	11.8	9.8
	Women	5.7	5.3
Nursing home	Men	16.9	17.1
	Women	22.4	22.3
Sheltered housing with 24-h assistance	Men	2.0 *	18.6
	Women	3.2 *	27.9

*Data in 2001-2003: the sheltered housing could be identified from the registers in year 2002 onwards.

4.4 Regression analysis of the association between the year of death and place of death

Women were less likely to die at home (OR=0.69) or in the specialized care hospitals (OR=0.56) than men. The likelihood of dying in the nursing home (OR=1.24), the sheltered housing with 24-hour assistance (OR=1.14), or in the primary care hospital (OR=1.10) was higher among women. The older age group was less likely to die at home or in hospitals than the youngest age group (70-79) at home or hospitals. The older age group was more likely to have the nursing home or the sheltered housing with 24-hour assistance as the place of death. The differences in home deaths and nursing home deaths were modest between the study years. The likelihood of dying at home decreased until 2010-2012, but there was no statistically significant difference between the reference years and 2013. On the contrary, the likelihood of dying in a nursing home

increased until the 2010-2012, but the difference between the reference years and 2013 was not statistically significant.

The changes in sheltered housing with 24-hour assistance were the most notable over time. The likelihood of people with dementia dying at the sheltered housing with 24-hour assistance increased. Since the reference years 2001-2003, the ratio of the year 2013 rose to 10.97. In contrast, the likelihood of dying in the primary care hospital decreased notably. The likelihood of dying in the specialized care hospital fluctuated between different years, but was lower in 2013 than in 1998-2000.

Table 5: The associations of death place, age, gender, and the death year for people with dementia. Odds ratios (ORs) and 95% confidence intervals with binary logistic regression models

Place of death	All (N=140003)	Home (N=8873)	Specialized care hospital (N=11235)	Primary care hospital (N=76684)	Nursing home (N=30609)	Sheltered housing with 24-h assistance (N=12489)
Gender (%)		ODD(95%CI)	ODD(95%CI)	ODD(95%CI)	ODD(95%CI)	ODD(95%CI)
Men	45689 (32.6)	ref	ref	ref	ref	ref
Women	94345 (67.4)	0.69 (0.66-0.72)*	0.56 (0.54-0.58)*	1.10 (1.07-1.12)*	1.24 (1.20-1.27)*	1.24 (1.18-1.29)*
Age at death (%)						
70-79	22170 (15.8)	ref	ref	ref	ref	ref
80-89	73414 (52.4)	0.80 (0.75-0.85)*	0.73 (0.69-0.77)*	0.94 (0.91-0.97)*	1.17 (1.12-1.22)*	1.39 (1.31-1.48)*
90+	44450 (31.7)	0.66 (0.62-0.70)*	0.45 (0.43-0.48)*	0.83 (0.81-0.86)*	1.58 (1.51-1.65)*	1.73 (1.63-1.85)*
Year of death (%)						
1998-2000	13617 (9.7)	ref	ref	ref	ref	ref
2001-2003	20615 (14.7)	0.70 (0.64-0.76)*	0.99 (0.91-1.08)*	0.90 (0.86-0.95)*	1.10 (1.04-1.16)*	ref
2004-2006	26537 (19.0)	0.69 (0.64-0.75)*	1.17 (1.09-1.27)*	0.80 (0.77-0.84)*	1.05 (1.00-1.11)	1.57 (1.42-1.74)*
2007-2009	30935 (22.1)	0.71 (0.66-0.77)*	1.09 (1.01-1.18)*	0.70 (0.67-0.73)*	1.10 (1.04-1.16)*	2.62 (2.38-2.87)*
2010-2012	35429 (25.3)	0.85 (0.79-0.91)*	1.02 (0.95-1.11)	0.47 (0.45-0.49)*	1.16 (1.10-1.22)*	5.83 (5.34-6.36)*
2013	12901 (9.2)	1.01 (0.92-1.10)	0.90 (0.82-0.99)*	0.34 (0.32-0.35)*	0.99 (0.93-1.05)	10.97 (10.01-12.02)*

Statistically significant odds ratios are marked with the *, which had significant at $p < 0.05$.

Adjusted for comorbidity, including cancer, diabetes, psychosis, depressive syndromes or other mental health disorders, Parkinson disease or other neurological diseases, chronic asthma and chronic obstructive pulmonary disease or other respiratory diseases, arthritis or osteoarthritis, hip fracture, stroke, ischemic and other heart disease excluding rheumatic and alcoholic diseases, and other diseases of the circulatory system.

Chapter 5: Discussion and Conclusions

Research questions were;

- 1) What are the places of death in people with dementia?
- 2) How the places of death differ between the different age group of 70-79, 80-89, and 90+, and between men and women?
- 3) How the places of death have changed between the years 1998 and 2013?

Contents of this chapter are;

- 5.1 Summary of the main findings
- 5.2 The relationship of my research to the previous researches
- 5.3 The strengths and weakness
- 5.4 Further research

5.1 Summary of the main findings

The most frequent place of death was the primary care hospital, followed by nursing home and sheltered housing with 24-hour assistance. In Finland, more than half of the people with dementia aged 70 or older died in the hospital (specialized care hospitals and primary care hospital were combined) during 1998-2013. During the past decades, the death in the primary care hospital decreased, and outpatient (community) LTC in sheltered housing with 24-hour assistance became a more frequent place of death. The proportion of home deaths remained about the same.

In Finland, the hospital has been an important place of death for people with dementia. Dying in the hospital, especially in the primary care hospital (the health center) that offers primary hospital care and LTC has been and still is very common. However, dying in the primary care hospital has decreased notably between the study years 1998-2013. Dying in specialized hospital care facilities was relatively rare, and the proportion of death in there did not change during the study years. Simultaneously, an entirely new form of LTC facility, sheltered housing with 24-hour assistance was initiated and became a prominent place of death for people with dementia. It is inferred that the health and social care policy reform from institutional care to outpatient long-term care last decades

affected this change. Dying at home was infrequent and did not evolve over time. As in the other Nordic welfare states, Finnish social and health care belongs to the responsibility of the state and municipalities rather than family (Anttonen and Häikiö, 2011, Anttonen and Sipilä, 1996). It might be one of the reason home death was rare in Finland.

With increasing age, the probability to die in a hospital or at home decreased, while dying in a LTC facility increased. For women, the likelihood of dying in the LTC facilities or a primary care hospital was higher than for men, who were more like to die in a specialized care hospital or at home.

Further, the proportion of older age group of women (90+) increased larger than it in men during the study year. During the study period, the likelihood of dying at nursing home and sheltered housing with 24-hour assistance was higher in women compared with men and older age group.

From these data showed that there are trends that dying at home were less to women and the most aged people. The older age at the time of death was associated with higher frequency of LTC facility deaths, thus growing longevity probably increases the LTC facility as the place of death. It applies in particular to women because almost a half of women with dementia died at the age of 90 or older in 2013 as shown in this study.

Though the national policy emphasizes staying at home as long as possible, this does not necessarily apply to people with dementia. The advanced stage of dementia particularly requires more intensive care, which may eventually result in patients being admitted into an institution (Gaugler et al., 2007, Etters et al., 2008). In addition to it, the long duration of the caregiving burdens a caregiver's personal health and life, leading to the early admission of the person with dementia to LTC facility or hospital (van der Steen, 2010, Mitchell et al., 2009, Jagger et al., 2000, Sachs et al., 2004). It might be the reason more deaths of women and older at LTC in 2013, and this trend may continue to grow in Finland. The decline in the number of older people in residential homes (6.1% fell compared with the previous year in the year 2010) was reported in Institutional care and housing services in social care 2014 as Finnish official statistics. Increasing the clients' number (= number of residents) in sheltered housing with 24-hour assistance and decreasing the number of clients in long-term care in health center wards were also stated.

(Väyrynen and Kuronen, 2016). As a consequence, the planning of the better setting of LTC at the EOL care for people with dementia is demanded urgently.

5.2 The relationship of my research to the previous research

Reyniers et al. (2015) noted that the death related dementia was 4.8% of all deaths in 14 European and non-European countries. There was a wide variation among the countries ranging from 0.4% in Mexico to 6.9% in Canada in this international comparison study. High percentages of death caused by dementia were reported in Belgium. 31% of people aged over 65 and 59% of the people with dementia died at the care home (Meeussen et al., 2012). In this study, the death related to dementia in Finland was 22.0% in 1998-2000 but rose to 33.9% in 2013. Official Statistics Finland (2013) confirmed this rapid increasing of the number of people with dementia from 1998. Even though, still we should consider the fact that the changes in the diagnostic criteria and practices in Finland might add to them (Wu et al., 2014). It may affect this high ratio of death related to dementia. Notwithstanding, compared with other countries the death associated with dementia in Finland is much greater than any other countries. Comparisons are difficult to make because of the differences in datasets. Data used Houttekier et al. (2010), and Reyniers et al. (2015) were mostly based on the sample of the population, not the whole population like in this study.

As Houttekier et al. (2011) suggested, the place of death of people indicates the health care utilization at the end of life and specifies how and what kind of social and health services are available to them. Broad et al. (2013) conducted a cross-national comparison of the death place using a large proportion of the older population (people aged over 65 years) among 45 populations. Among the total over 16 million' deaths, one-fifth were in the residential aged facility (=LTC facility), and there were trends the percentages of dying at LTC facility were doubling with each 10-year increase in age, and 40 % higher among women. These age and gender trends of dying at LTC facility was found in my study.

The place of death for people with dementia varies in Europe. Dying in hospital ranged between 1.6% (Netherlands) and 62.3% (Hungary), nursing home death

between 20.1% (Spain) and 93.1% (Netherlands). Home death was rare (3.3-5.0%) in northern Europe but more frequent in southern Europe (27.2-46.1% in France, Spain, and Italy) (Houttekier et al., 2010, Reyniers et al., 2015).

In New Zealand and North American continent countries, older people are dying in Long-Term Care (LTC) facility (59.9-76.6%) more than in hospital (13.2-32.3%) or at home (3.4-15.3%) (Mitchell, 2005, Reyniers et al., 2015, Teno et al., 2004, 2013, Ganguli et al., 2005, Miller et al., 2012). An American national study of the death place for people with dementia described that the majority of older with dementia (over 65 years) died in nursing homes (66.9%) (Mitchell, 2005). Interestingly, older Japanese-American in the USA had a higher percentage of hospital death than Caucasian older Americans. 43% of death related to dementia was in the hospital (contrasted with 16% in a national study) and death at nursing home was 37% (contrasted with 67% in a national study). (Bell et al., 2009). On the contrary, increasing the distribution of supportive care such as palliative care, or hospice care had effect on more people dying at home recently in the USA. Hence, death related to dementia at home increased to 22.8% in 2009 from 19.9% in 2000 of Medicare beneficiaries. (Teno et al., 2013).

In Finland, still many people with dementia died at the hospital but the proportion of the hospital death has gradually decreased. This reduction occurred in the primary care hospital. Reduced number of those who died at the primary care hospital are likely associated with the fact that previously LTC was offered in the primary care hospital inpatient wards, but the current idea is that the health center should only provide hospital care, not long-term care. As a result, the number of people who received LTC in the primary care hospital has decreased. (Vidlund and Preusker, 2014).

It was found that even though the number is not as high as it is in the primary care hospital, recently more people with dementia have as sheltered housing with 24-hour assistance as the place of death in this study. The proportion of death at the sheltered housing with 24-hour assistance among the total death was nearly six times higher in 2013 (24.7%) than in 2001-2003 (4.4%). The nursing home death remained about the same during the study period. This is due to the health and social care policy change, which emphasizes living in the community instead of institutions. All of older people are encouraged to stay at home as long as possible. This is possible if the adequate

home care was provided and if the help from informal caregivers is available at home. However, as the symptoms worsen the people with dementia are moving into the care homes, the nursing home or sheltered housing with 24-hour assistance, especially the sheltered housing with 24-hour assistance.

Recently, it was suggested the physical environment at the EOL care has a remarkable influence on dementia care (Day et al., 2000). Many studies noted that a small, home-like environment is beneficial for older people with dementia (Calkins, 2001, Day et al., 2000; Judd et al., 1998; Sloane et al., 1998). Also, alongside developing the dementia care research, new therapeutic environments have been proposed for people with dementia. Those new ideas emphasize the normalization of daily life: the environment is small and home-like, and the care is person-centered with respect for residents' needs and desires. Various countries have implemented the home-like setting for the EOL care little differently such as group living in Sweden (Annerstedt, 1993), Netherlands (te Boekhorst et al., 2008), and Belgium (de Rooij et al., 2012), group homes in Japan (Onishi et al., 2006, Hirakawa et al., 2006), the Green House in the USA (Kane et al., 2007), Domuses in the UK (Lindesay et al., 1991), and residential groups home in Germany (Palm et al., 2014). The structure of sheltered housing with 24-hour assistance in Finland is similar to the small group setting.

Globally, there are the changes in the living place of people with dementia over time alongside their physical and mental conditions progress, from hospitals to care homes were seen in EU countries, from hospital to home in the USA and Sweden (Spethman, 2013). The shift of moving to the care home once the symptom worsened seems the worldwide trend. From my study, it is evident the trends in Finland seem to follow this direction, especially into sheltered housing with 24-hour assistance. Near the future, the number of residents in LTC facilities grow and sheltered housing with 24-hour assistance increase. It is likely sheltered housing with 24-hour assistance would be the dying place for people with dementia in Finland.

This change in Finland originates to LTC reform that favors LTC offered in care sites classified as outpatient care, but also to the increasing longevity. Based on previous studies (te Boekhorst et al., 2008, de Rooij et al., 2012) the results imply that compared with hospital LTC facilities are a more appropriate place for the EOL care for

people with dementia. There is lack of extensive research describing the quality of EOL care in this relatively new type of LTC facilities. It is possible that the quality of care has not entirely reached the particular needs of those dying with dementia in this still ongoing LTC reform.

5.3 The strengths and weakness

This study is the first report of the trend of the changes in places of death of people with dementia in Finland. The analysis using extensive data (Finnish Mortality data during 1998-2013, which totaled 140034) provide us the valuable features of the death and the care place for the entire population of people with dementia over 70 years old in this study period of 1998-2013.

A major strength of this study is the extensive and reliable data drawn from the Causes of Death Register and the health and social care registers. In Finnish the death certificate system, the death certificates include the cause of death and the socio-demographic characteristics of the deceased. A physician writes down the cause of death and certifies the causal chain of diseases starting with the underlying cause of death. Death certificates have been available since the year of 1936 in Statistics Finland's archive. Information from the death certificates, the causes of death are encoded in ICD-10 codes, which allow us to compare with other countries. The places of death are drawn from health and social care registers.

Over the world, all deaths at the population level are available in only a few countries. Even in the developed countries, the availability is limited. In previous studies, conducted in different countries, datasets do not cover the entire population but only the sample of the population. In this study, the analysis was done using a whole demographic data based on the national register system. Are the changes of care setting at the EOL care for people with dementia from the findings of my study similar to the other developed countries' movement? Or, are there unique trends in Finland compared with other countries? In the future, if some researchers may interest to use this Finnish total population data, those questions would be the interest of international comparison to the further research project as well.

There is also the weakness to be considered. This study lacks information on social relationships and availability of informal care, the level of income, functional ability, and the stage of dementia, which all contribute to the use of care. Symptoms in dementia progress slowly and the progress of the disease is unpredictable, and sometimes diagnosis of dementia is not clear. The dementia stages have a strong impact for the care need. In the severe stage of dementia, people may be forced to move into the care homes such as nursing home, primary care hospital, or sheltered housing with 24-hour assistance. Further research should concentrate on the effect of the stage of dementia related to the transferring and the death place.

Since 1996 Finland use ICD10, the International Classification of Diseases, but in 2005, Finnish government, Finnish national health and social care registers decided to use an international guideline (the WHO guideline) that limits the use of pneumonia as an underlying cause of death in connection with several chronic diseases. The Causes of Death Register in Finland select dementia as the cause of death if a person has both pneumonia and dementia (Official Statistics Finland, 2013), this might affect the increase of dementia in the cause of death statistics. It might influence the growth in dementia as the underlying cause of death. Also, we did not have information about the quality of care these people received in immediate death. Thus, we can only speculate about that.

5.4 Further research

Recent trends of fast ageing population and growing the prevalence of dementia demand a high need for beds in LTC facility (Houttekier et al., 2011). In Finland dying in LTC facility increased, especially sheltered housing with 24-hour assistance became a more frequent place of death. Care facilities including traditional nursing home and sheltered housing with 24-hour assistance could specialize as the primary site of the EOL care for people with dementia in the future. LTC offered in primary care hospital inpatient wards is decreasing. The economic inferences of these trends are critical and should be considered. As a result of the unique feature of recent reform in the Finnish elderly care system, there is a transition from the universal social delivery system based on the public responsibility to the market-friendly delivery system, or the marketization

of social and health care. When private companies offer the LTC, it is partially paid by the municipality with the public funding and federal authorities regulate this marketization. However, the marketization is enlarging. (Anttonen and Häikiö, 2011). There should a continuous research evaluating how the changing system affects the delivery and the quality of EOL care for people with dementia.

Even though the trend of increasing outpatient care such as sheltered housing with 24-hour assistance services and home care services for the EOL care for people with dementia, many of them ended up in the hospital in the last three months (Aaltonen et al., 2012). It may be the reason the proportion of the death in the specialized hospitals did not change in this study. If a person admitted to specialized care hospital, physicians are more likely to choose vigorous acute care at the end of life for them according to the Finnish survey study (Hinkka et al., 2002). In the advanced stage of dementia, the transition at the end of life might become burdensome (Naylor et al., 2005, Callahan et al., 2012, Gozalo et al., 2011) and raise the risk of medical errors such as administering the wrong intravenous antibiotics in the hospital or unnecessary treatments (Meier and Beresfors, 2008, Coleman, 2003, Naylor et al., 2004). Related the death place the transition before death should be further searched for making the better social and health care system for people with dementia in Finland.

In the future, it would be important to study how people with dementia end up in the last care site. To evaluate the effects of changing health and social care system in how care is organized at the end of life, it would be necessary to study the well-being of people with dementia and their caregivers including formal and informal caregivers.

Chapter 6: Recommendations for policy or practice

It is evident that studying trends in place of death is important to investigate and evaluate and to plan future EOL care services. Due to the ageing of the population all over the world, chronic life-limiting conditions such as dementia-related diseases will become more crucial. The EOL care in care facility will become a major apprehension because of the expected increase in care home residents (Martikainen et al., 2012). Thus there will be an increasing need for developing and improving care at the end of life in different care sites. EOL care in various diseases has been studied widely, but due to increasing longevity and changing care needs, timely research is needed.

The palliative care was introduced as the active total care of incurable disease patients by the World Health Organization (WHO, 1990). European Association for Palliative Care (EAPC) firmly stated dementia as a terminal illness and recommended to be provided adequate palliative care as all treatment and care in dementia (EAPC, 2013). Unfortunately, instead of the growing number of death related to dementia palliative care delivery is still limited to them (Mitchell et al., 2009). Further, palliative care is not used enough in dementia (Hurley et al., 2000, Sampson et al., 2006, Bayer, 2006, Meeussen et al., 2012).

In Finland, the Finnish National Board of Health started to distribute the instructions for terminal care according to the guideline of EPAC since 1982, and subsequently, the National Board, the Lutheran church, and the voluntary sector has adopted the specialty (Vainio, 1990). According to current Finnish care guidelines, every health care facility, i.e. hospital, should have the ability to offer palliative care (National Center for Health Statistics, 2011). Also National Supervisory Authority for Welfare and Health (Valvira) provides recommendations for palliative care. However, in fact, the research is scarce and focuses on the terminal cancer cases at the university hospital and primary care (Tasmuth et al., 2006). The Finnish support system by social and health care policy for treatment and care in dementia should be established at the same level of the system to the terminal phase of cancer, at least.

The increasing of death at the sheltered housing with 24-hour assistance is the tremendously recent trend in Finland. It is partially from Finnish elderly-care policies transition based on the financial status (Anttonen and Häikiö, 2011). As a consequence, what kind of the EOL care at those care facilities are offering is a matter of discussion recently. Palliative care should be studied how well and to what extent palliative care is provided in the sheltered housing with 24-hour assistance or other institutional care setting and maybe also in hospitals, especially to other than cancer patients.

Further, related to use palliative care at the EOL care for people with dementia, dementia should be considered as a terminal illness. Under this viewpoint, the EOL care needs to be improved with appropriate care planning, well trained skilled care staff, decision-making communication at the early stage among people with dementia including care medical staff and family.

References

- Aaltonen, M., Rissanen, P., Forma, L., Raitanen, J., and Jylhä, M. (2012) The impact of dementia on care transitions during the last two years of life. *Age and Ageing*, **41**, 52–57.
- Aaltonen, M., Raitanen, J., Forma, L., Pulkki, J., Rissanen, P. and Jylhä, M. (2014) Burdensome Transitions at the End of Life Among Long-Term Care Residents With Dementia. *J of the American Medical Directors Association*, **15**(9), 643 – 648.
- Agüero-Torres, H, von Strauss, E., Viitanen, M, Winblad, B, Fratiglioni, L. (2001) Institutionalization in the elderly: The role of chronic diseases and dementia. Cross-sectional and longitudinal data from a population-based study. *Journal of Clinical Epidemiology*, **54**, 795–801.
- Alzheimer's association report 2013. (2013) Alzheimer's disease facts and figures. *Alzheimer's disease and Dementia*, **9** (2), 208-245.
- American Psychiatric Association. (2013) Diagnostic and statistical manual of mental disorders (5th edition). American Psychiatric Publishing, Arlington, Va.
- Anell, A. (2016) The public-private pendulum-patient choice and equity in Sweden. *N. Engl. Med.* **373** (1), 1-4.
- Annerstedt L. (1993) Development and consequences of group living in Sweden. A new mode of care for the demented elderly. *Soc Sci Med*, **37** (12), 1529-1538.
- Anttonen, A and Häikiö, L. (2011) Care 'going market': Finnish elderly-care policies in transition. *Nordic J. of Social Research*, **2** (Special issue), 70-90.
- Anttonen, A and Sipilä, J. European social care services. *Journal of European Social Policy*, **6** (2) (1996), pp. 87–100.
- Badrakalimuthu, V and Barclay, S. (2014) Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and Ageing*, **43**, 13–19.
- Barnes, L.L., Wilson, R.S., Schneider, J.A., Bienias, J.L., Evans, D.A., Bennett, D.A. (2003) Gender, cognitive decline, and risk of AD in older persons. *Neurology*, **60** (11), 1777–1781.
- Bayer, A. (2006) Death with dementia - the need for better care. *Age and Ageing*, **35**, 101–102.
- Bell, C. L., Davis, J., Harrigan, R. C., Somogyi-Zalud, E., Tanabe, M. K. G., and Masaki, K. H. (2009) Factors associated with place of death for elderly Japanese-American men: The Honolulu Heart Program and Honolulu-Asia Aging Study. *J Am Geriatric Soc*, **57** (4), 714–718. doi:10.1111/j.1532-5415.2008.02149.x.

- Brayne, C., Gao, L., Dewey, M., Matthews, F. E., (2006) Medical Research Council Cognitive Function and Ageing Study Investigators. Dementia before death in ageing societies-The promise of prevention and the reality. *PLoS Med*, **3** (10): e397. DOI: 10.1371/journal.pmed.0030397
- Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., and Connolly, M. J. (2013) Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health*, **58**, 257–267.
- Callahan, C. M., Arling, G., Tu, W., Rosenman, M. B., Counsell, S. R., Stump, T. E. and Hendrie, H. C. (2012) Transitions in Care for Older Adults with and without Dementia. *J Am Geriatr Soc*, **60**, 813–820.
- Calkins, M. P. (2001) Creating Successful Dementia Care Settings. Health Professions Press. Baltimore, MD, pp. 374-393.
- Chang, A. and Walter, L. C. (2010) Recognizing dementia as a terminal illness in nursing home residents: Comment on "Survival and comfort after treatment of pneumonia in advanced dementia". *Arch Intern Med*, **170** (13), 1107-1109. doi: 10.1001/archinternmed.2010.166.
- Christensen, k., Doblhammer, G., Rau, R. and Vaupel, J. W. (2009) Ageing populations: the challenges ahead. *Lancet*, **374** (3), 1196-1208.
- Coleman, E. A. (2003) Falling Through the Cracks: Challenges and Opportunities for Improving Transitional Care for Persons with Continuous Complex Care Needs. *J Am Geriatr Soc*, **51**, 549–555.
- Corrada, M. M., Brookmeyer, R., Berlau, D, et al. (2008) Prevalence of dementia after age 90: results from the 90+ Study. *Neurology*, **71**, 337–343.
- Corrada, M. M., Brookmeyer, R., Paganini-Hill, A., Berlau, D., and Kawas, C. H. (2010) Dementia Incidence Continues to Increase with Age in the Oldest Old The 90+ Study. *Ann Neurol*, **67** (1), 114–121. doi:10.1002/ana.21915
- Day, K., Carreon, D. and Stump, C. (2000) The therapeutic design of environments for people with dementia: a review of the empirical research. *Gerontologist*, **40**, 397–416.
- de Rooij, A. H., Luijkx, K. G., Schaafsma, J., Declercq, A. G., Emmerink, P. M., Schols, J. M. (2012) Quality of life of residents with dementia in traditional versus small-scale long-term care settings: a quasi-experimental study. *Int J Nurs Stud*, **49** (8), 931-940. doi: 10.1016/j.ijnurstu.2012.02.007. Epub 2012 Mar 16.
- Dodge, H. H., Buracchio, T. J., Fisher, G. G., et al. (2012) Trends in the Prevalence of Dementia in Japan. *Int. J. of Alzheimer's Disease*, **2012**, Article ID 956354, 11 pages. <http://dx.doi.org/10.1155/2012/956354>.

EAPC. (2013) Recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias. EAPC DEMENTIA WHITE PAPER – JUNE 2013. Supplement to the white paper published on Palliative Medicine 2013; 0(0) 1-13, <http://pmj.sagepub.com/content/28/3/197.full.pdf+html>.

Edvardsson, D., Fetherstonhaugh, D., and Nay, R. (2010) Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *J Clin Nurs*, **19** (17-18), 2611-2618. doi: 10.1111/j.1365-2702.2009.03143.x. Epub 2010 Jun 25.

Engel, S. E., Kiely, D. K., and Mitchell, S. L. (2006) Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *J Am Geriatr Soc*, **54**, 1567–1572.

Etters, L., Goodall, D. and Harrison, B. E. (2008) Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners*, **20**, 423–428.

Evans, D. A., Bennett, D. A., Wilson, R. S., et al. (2003) Incidence of Alzheimer Disease in a Biracial Urban Community: Relation to Apolipoprotein E Allele Status. *Arch Neurol*, **60**(2), 185-189. doi:10.1001/archneur.60.2.185.

Falk, C. K. (2013). Elder abuse in nursing homes: the impact of dementia/special care units (Doctoral dissertation), University of Illinois at Urbana-Champaign. USA.

Ferri, C. P., Prince, M., Brayne, C., et al. (2005) Global prevalence of dementia: a Delphi consensus study. *Lancet*, **366**, 2112–2117.

Fillenbaum, G. G., Heyman, A., Huber, M. S., Woodbury, M. A., Leiss, J., Schmader, K. E., et al. (1998) The prevalence and 3-year incidence of dementia in older black and white community residents. *J Clin Epidemiol*, **51** (7), 587–595.

Fitzpatrick, A. L., Kuller, L. H., Ives, D. G., Lopez, O. L., Jagust, W., Breitner, J. C., et al. (2004) Incidence and prevalence of dementia in the Cardiovascular Health Study. *J Am Geriatr Soc*, **52** (2), 195–204.

Friedrich L. (2013) End-of-life nutrition: is tube feeding the solution? *Annals of Long-Term Care: Clinical Care and Aging*, **21**(10), 30-33.

Ganguli, M., Dodge, H. H., Shen, C., Pandav, R. S., DeKosky, S. T. (2005) Alzheimer disease and mortality: a 15-year epidemiological study. *Arch Neurol*, **62** (5), 779-784.

Gaugler, J. E., Duval, S., Anderson, K. A. and Kane, R. L. (2007) Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatrics*, **7**, 13-17.

Givens, J. L., Jones, R. N., Shaffer, M. L., Kiely, D. K., Mitchell, S. L. (2010) Survival and comfort after treatment of pneumonia in advanced dementia. *Arch Intern Med*, **170** (13), 1102-1107.

Givens, J. L., Selby, K., Goldfield, K. S., and Mitchell, S. L. (2012) Hospital Transfers Among Nursing Home Residents With Advanced Dementia. *J Am Geriatr Soc*, **60** (5), 905–909. doi:10.1111/j.1532-5415.2012.03919.x.

Gozalo, P., Teno, J. M., Mitchell, S. L., Skinner, J., Bynum, J., Tyler, D. and Mor, D. (2011) End-of-Life Transitions among Nursing Home Residents with Cognitive Issues. *N Engl J Med*, **365**, 1212-1221.

Halpern, S. (2015) Toward evidence-based end-of-life care. *N. Engl. Med*, **372** (1), 1-3.

Hakkinen, U. (2005) The impact of changes in Finland's health care system. *Health Econ*, **14**, S101–S118.

Published online in Wiley Inter Science (www.interscience.wiley.com).

DOI:10.1002/heh.1030

Harris, D. (2007) Forget me not: palliative care for people with dementia. *Postgrad Med J*, **83**, 362–366. doi: 10.1136/pgmj.2006.052936

Hebert, L. E., Scherr, P. A., McCann, J. J., Beckett, L. A., Evans, D. A. (2001) Is the risk of developing Alzheimer's disease greater for women than for men? *Am J Epidemiol*, **153** (2), 132-136.

Hebert, L. E., Weuve, J., Scherr, P. A., Evans, D. A. (2013) Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, **80** (19), 1778-1783. doi: 10.1212/WNL.0b013e31828726f5. Epub 2013 Feb 6.

Hinkka, H., Kosunen, E., Lammi, U-K., Metsanoja, R., Puustelli, A., and Kellokumpu-Lehtinen, P. (2002) Decision making in terminal care: a survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. *Palliative Medicine*, **16**, 195- 204.

Hirakawa, Y., Masuda, Y., Uemura, K., Kuzuya, M., Kimata, T., and Iguchi, A. (2006) End-of-life care at group homes for patients with dementia in Japan Findings from an analysis of policy-related differences. *Archives of Gerontology and Geriatrics*, **42**, 233–245.

Houttekier, D., Cohen, J., Bilsen, J., et al. (2010) Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc*, **58** (4), 751–756.

Houttekier, D., Cohen, J., Surkyn, J. and Luc Deliens, L. (2011) Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health*, **11**, 228-237.

Houttekier, D., Vandervoort, A., Van den Block, L., van der Steen, J.T., Vander, S. R., Deliens, L. (2014) Hospitalizations of nursing home residents with dementia in the last month of life: results from a nationwide survey. *Palliat Med*, **28** (9), 1110-1117. doi: 10.1177/0269216314535962. Epub 2014 May 27.

Hurley, A. C., Volicer, L. and Blasi, Z. V. (2000) End-of-life care for patients with advanced dementia. *JAMA*, **284**, 2449–2450.

Iwatsubo, T et al. (2006) Alzheimer disease research in Japan: public funding. *Nature Medicine*, **12** (7), 778-779.

Jagger, C., Andersen, K., Breteler, M. M., Copeland, J. R., Helmer, C., Baldereschi, M., Fratiglioni, L., Lobo, A., Soininen, H., Hofman, A., Launer, L. J. (2000) Prognosis with dementia in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. *Neurology*, **54** (11 Suppl 5), S16-20.

Jorm, A. F. and Jolley, D. (1998) The incidence of dementia: a meta-analysis. *Neurology*, **51** (3), 728-733.

Judd, S. (1998) Building for Dementia: A matter of design, in Judd, S., Marshall, M., Phippen, P. (Eds) *Design Dementia*, Journal of Dementia Care, London: Hawker Publications, pp. 15-18.

Kane, R. A., Lum, T. Y., Cutler, L. J., Degenholtz, H. B., and Yu, T. C. (2007) Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program. *J Am Geriatr Soc*, **55**, 832–839.

Kitwood, T. (1988) “The Technical, the Personal, and the Framing of Dementia.” *Social Behaviour*, **3**, 161–179.

Kitwood, T. (1997a) *Dementia Reconsidered: The Person Comes First..* Buckingham, UK: Open University Press.

Kitwood, T. (1997b) “Towards a Theory of Dementia Care: Personhood and Well-being.” *Ageing & Society*, **12**, 269–287.

Knapp, M., Comas-Herrera, A., Somani, A., Banerjee, S. (2007) *Dementia: International comparisons. Summary report.* London: National Audit Office. www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx

Koren, M. J. (2010) “Person- Centered Care for Nursing Home Residents: The Culture Change Movement.” *Health Affairs*, **29** (2), 312–317.

Kovach, C. R., Weissman, D. E., Griffie, J., Matson, S. and Muchka, S. (1999) Assessment and Treatment of Discomfort for People with Late-Stage Dementia. *Journal of Pain and Symptom Management*, **18** (6), 412-419.

Kukull, W. A. (2006) The growing global burden of dementia. *The Lancet Neurology*, **5** (3), 199–200.

Kukull, W.A., Higdon, R., Bowen, J. D., McCormick, W. C., Teri, L., Schellenberg, G. D, et al. (2002) Dementia and Alzheimer disease incidence: A prospective cohort study. *Arch Neurol*, **59** (11), 1737–1746.

Lamberg, J. L., Person, C. J., Kiely, D. K., Mitchell, S. L. (2005) Decisions to hospitalize nursing home residents dying with advanced dementia. *J Am Geriatr Soc*, **53** (8), 1396-1401.

- Lewis, S. (2015) A system in name only-access, variation, and reform in Canada's provinces. *N. Engl. Med*, **372** (6), 497-500.
- Lindesay, J., Briggs, K., Lawes, M., MacDonald, A., and Herzberg, A. (1991) The domus philosophy: A comparative evaluation of a new approach to residential care for the demented elderly. *International Journal of Geriatric Psychiatry*, **6** (10), 727–736.
- Martikainen, P, Murphy, M, Metsä-Simola, N, Häkkinen, U, and Moustgaard, H. (2012) Seven-year hospital and nursing home care use according to age and proximity to death: variations by cause of death and socio-demographic position. *J Epidemiol Community Health*, **66** (12), 1152-1158. doi: 10.1136/jech-2011-200756. Epub 2012 Apr 27.
- Marshall, M. (2015) A precious jewel-the role of general practice in the English NHS. *N. Eng. Med*, **372** (10), 893-897.
- McCann, R. M., Hall, W. J., Groth-Juncker, A. (1994) Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA*, **272** (16), 1263-1266.
- McCurry, J. (2015) Japan will be model for future super-ageing societies. *Japan Lancet World Report*, **386** (17), 1523. www.thelancet.com
- Meeussen, K., Van den Block, L., Echteld, M., Boffin, N., Bilsen, J., Van Casteren, V. and Deliens, L. (2012) Older people dying with dementia: a nationwide study. *International Psychogeriatrics*, **24** (10), 1581–1591.
- Meier, D. E. and Beresford, L. (2008) Palliative care's challenge: facilitating transitions of care. *J. Palliat. Med.* **11** (3), 416-421.
- Miller, S. C., Lima, J. C., Looze, J, and Mitchell, S. L. (2012) Dying in U.S. Nursing Homes with Advanced Dementia: How Does Health Care Use Differ for Residents with, versus without, End-of-Life Medicare Skilled Nursing Facility Care? *J. of Palliative Medicine*, **15** (1), 43-50.
- Mitchell, S. L. (2005) A national study of the location of death for older persons with dementia. *J Am Geriatr Soc*, **53**, 299–305.
- Mitchell, S. L., Kiely, D. K., Hamel, M. B. (2004) Dying with advanced dementia in the nursing home. *Arch Intern Med*, **164** (3), 321-326.
- Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L. and Hamel, M. B. (2009) The Clinical Course of Advanced Dementia. *N Engl J Med*, **361**, 1529-1538.
- Moise, P., Schwarzingler, M. and Um, M. (2004) Dementia Care in 9 OECD Countries: A Comparative Analysis. Paris: OECD.
- Morrissey, S., Blumenthal, D., Osborn, R., Cufman, G.D. and Malina, D. (2015) International health care systems. *N Eng J Med*, **372** (1), 75-76.

- Mura, T., Dartigues, J., Berr, C. (2010) How many dementia cases in France and Europe? Alternative projections and scenarios 2010–2050. *Eur J Neurol*, **17**, 252–259.
- National Center for Health Statistics. Health, United States, 2010: With Special Feature on Death and Dying. Hyattsville, MD. 2011
- Naylor, M. D., Brooten, D. A., Campbell, R. L., Maislin, G., McCauley, K. M., Schwartz, J. C. (2004) Transitional care of older adults hospitalized with heart failure: A randomized controlled trial. *J Am Geriatr Soc*, **52**, 675–684.
- Naylor, M. D., Stephens, C., Bowles, K. H., Bixby, M. B. (2005) Cognitively impaired older adults: from hospital to home. *Am J Nurs*, **105**, 52–61.
- Nihtila, E. K. and Martikainen, P. (2007) Household income and other socio-economic determinants of long-term institutional care among older adults in Finland. *Population Studies*, **61**(3): 299–314.
- Nihtilä, E. K., Martikainen, P. T., Koskinen, S. V., Reunanen, A. R., Noro, A. M., and Häkkinen, U. T. (2008) Chronic conditions and the risk of long-term institutionalization among older people. *European Journal of Public Health*, **18** (1), 77–84.
- OECD 2012: www.oecd.org/dataoecd/52/31/38/23085.xls
- Official Statistics Finland. Official Statistics of Finland 2013 (OSF): Causes of death [e-publication]. ISSN=1799-5078. Helsinki: Statistics Finland [referred: 16.12.2015]. Access method: http://www.stat.fi/til/ksyyt/kas_en.html
- Official Statistics of Finland (OSF) 2015: Causes of death [e-publication]. ISSN=1799-5078. 2014, 1. Causes of death in 2014. Helsinki: Statistics Finland [referred: 9.2.2016]. Access method: http://www.stat.fi/til/ksyyt/2014/ksyyt_2014_2015-12-30_kat_001_en.html
- Official Statistics of Finland (OSF) 2015: Causes of death [e-publication]. ISSN=1799-5078. 2014, 3. Deaths from dementia and Alzheimer's disease are increasing. Helsinki: Statistics Finland [referred: 9.2.2016]. Access method: http://www.stat.fi/til/ksyyt/2014/ksyyt_2014_2015-12-30_kat_003_en.html
- Onishi, J., Suzuki, Y., Umegaki, H., Endo, H., Kawamura, T., Imaizumi, M. and Iguchi, A. (2006) Behavioral, psychological and physical symptoms in group homes for older adults with dementia. *International Psychogeriatrics*, **18** (1), 75–86. doi:10.1017/S1041610205002917
- Palm, R., Bartholomeyczik, S., Roes, M. and Holle, B. (2014) Structural characteristics of specialised living units for people with dementia: a cross-sectional study in German nursing homes. *International Journal of Mental Health Systems*, **8**, 39–48.
- Perreels, A. J., Fleming, J., Zhao, J. et al. (2014) Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective

analysis of a prospective population-based cohort aged 85 and over. *Palliat Med*, **28**, 220–233.

Pinzon, L. C. E., Claus, M., Perrar, K. M., Zepf, K. I., Letzel, S., & Weber, M. (2013). Dying With Dementia: Symptom Burden, Quality of Care, and Place of Death. *Deutsches Ärzteblatt International*, *110*(12), 195–202. <http://doi.org/10.3238/arztebl.2013.0195>

Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., Burke, J. R., Hurd, M. D., Potter, G. G., Rodgers, W. L., Steffens, D. C., Willis, R. J., Wallace, R. B. (2007) Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology*, **29**, 125–132.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., Ferri, C. P. (2013) The global prevalence of dementia: a systematic review and meta analysis. *Alzheimers Dement*, **9** (1), 63-75. e2. doi: 10.1016/j.jalz.2012.11.007.

Rechel, B., Grundy, E., Robine, J. M., Cylus, J., Mackenbach, J.P., Knai, C., McKee, M. (2013) Ageing in the European Union. *Lancet*, **381** (9874), 1312-1322. doi: 10.1016/S0140-6736(12)62087-X. Epub 2013 Mar 27.

Reyniers, T., Deliens, L., Pasman, HR., Morin, L., Addington-Hall, J., Frova, L., Cardenas-Turanzas, M., Onwuteaka-Philipsen, B., Naylor, W., Ruiz-Ramos, M., Wilson, DM., Loucka, M., Csikos, A., Rhee, YJ., Teno, J, Cohen, J., and Houttekier, D. (2015) International Variation in Place of Death of Older People Who Died From Dementia in 14 European and non-European Countries. *JAMDA*, **16**, 1.

Sachs GA, Shega JW, Cox-Hayley D. (2004) Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med*, **19**, 1057-63.

Sampson, E.L., Gould, V., Dan Lee, L. and Blanchard, M. R. (2006) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age Ageing*, **35** (2), 187-189. doi: 10.1093/ageing/afj025

Seshadri, S., Wolf, P. A., Beiser, A., Au, R., McNulty, K., White, R., D'Agostino, R. B. (1997) Lifetime risk of dementia and Alzheimer's disease. The impact of mortality on risk estimates in the Framingham Study. *Neurology*, **49** (6), 1498-1504.

Sleeman, K. E., Ho1, Y. K., Verne, J., Gao1, W. and Higginson, I. J. on behalf of the GUIDE_Care project. (2014) Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010. *BMC Neurology*, **14**, 59.

Sloane P. D., Mitchell C. M., Preisser J. S., Phillips P., Commander C., Burkner E. (1998) Environmental correlates of resident agitation in Alzheimer's disease special care units. *Journal of the American Geriatrics Society*, **46**, 1-8.

Spethman, A. (2013) Changes in place of death in Sweden, 2004-2011. A study of urban elderly receiving public eldercare services. Master's thesis. University of Tampere, School of Health Sciences.

Stakes (2014) Care and Services for older people. Statistical report 26/2013.

Stewart-Archer, L. A., Afghani, A., Toye, C. M. and Gomez, F. A. (2015) Dialogue on Ideal End-of-Life Care for Those with Dementia. *American Journal of Hospice & Palliative Medicine*, 32(6):620-30. doi: 10.1177/1049909114532342. Epub 2014 Apr 29.

Stock, S. (2015) Integrated ambulatory specialist care-Germany's new health care sector. *N. Engl. Med.*, **372** (19), 1781-1785.

Tasmuth, T., Saarto, T., & Kalso, E. (2006). How palliative care of cancer patients is organised between a University Hospital and primary care in Finland. *Acta Oncologica*, 45(3), 325-331. doi:10.1080/02841860500423898

te Boekhorst, S., Pot, A.M., Depla, M.F.I.A., Smit, D., De Lange, J. and Eefsting, J.A. (2008) Group living homes for older people with dementia: the effects on psychological distress of informal caregivers. *Aging & Mental Health*, **12** (6), 761-768.

Teno, J. M., Clarridge, B. R., Casey, V., Welch, L.C., Wetler, T., Shield, R., Mor, V. (2004) Family perspectives on end-of-life care at the last place of care. *JAMA*, **291** (1), 88-93.

Teno, J. M., Gozalo, P. L., Bynum, J. P. W., Leland, N. E., Miller, S. C., Morden, N. E., Scupp, T., Goodman, D. C., Mor, V. (2013) Change in End-of-Life Care for Medicare Beneficiaries Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. *JAMA*, **309** (5), 470-477.

Teperi, J., Michael, E. Porter, M. E., Vuorenkoski, L. and Baron, J. F. (2009) The Finnish Health Care System: A Value-Based Perspective. Sitra Reports 82 ISBN 978-951-563-659-1 (URL:<http://www.sitra.fi>)

Tucker, S., Hughes, J., Burns, A., and Challis, D. (2008) The balance of care: Reconfiguring services for older people with mental health problems. *Aging & Mental Health*, **12** (1), 81-91.

Vainio, A. (1990) Palliative care in Finland. *Palliat Med*, **4**: 225-227. doi:10.1177/026921639000400311

van der Steen, J. T. (2010) Dying with Dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease*, **22**, 37-55. DOI 10.3233/JAD2010100744

van Ginneken, E. (2016) Perennial health care reform-the long Dutch quest for cost control and quality improvement. *N Engl. Med.* 373 (10): 885-889.

van Zadelhoff, E., Verbeek, H., Widdershoven, G., van Rossum, E., and Abma, T. (2011) Good care in group home living for people with dementia. Experiences of residents, family and nursing staff. *Journal of Clinical Nursing*, **20**, 2490-2500.

Valvira , available only in Finnish,
http://www.valvira.fi/terveydenhuolto/hyvaammattinharjoittaminen/elaman_loppuvaiheen_hoito/palliativinen-hoito)

Väyrynen, R and Kuronen, R. (2016) Institutional care and housing services in social care 2014. Statistical report 21/2015, 30.10.2015.

Official Statistics of Finland, Institutional Care and Housing Services in Social Care. THL

<https://www.thl.fi/en/web/thlfi-en/statistics/statistics-by-topic/social-services-older-people/institutional-care-and-housing-services-in-social-care>

Verbeek, H., van Rossum, E., Zwakhalen, S. M. G., Kempen, G. I. J. M. and Hamers, P. H. (2009) Homelike care environments for older people with dementia: a review. *International Psychogeriatrics*, **21** (2), 252–264.

Verbeek, H., Meyer, G., Leino-Kilpi, H., Zabalegui, A., Hallberg, I. R., Saks, K., Soto, M. E., Challis, D., Sauerland, D. and Hamers, J. P. H. (2012) A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. *BMC Public Health*. 12(1): 1-10.

Vidlund, M and Preusker, U. (2014) Country Document Update 2014, Pensions, health and long-term care, Finland March 2014. asisp country document update 2014 Finland ec.europa.eu/social/BlobServlet?docId=12955&langId=en

Volicer, L. (2005) End-of-life Care for People with Dementia in Residential Care Settings. actionalz.org/www.actionalz.org

Voutilainen P., Kattainen E., Heinola R. (2007) ”Omaishoidon tuki sosiaalipalveluna. Selvitys omaishoidon tuesta ja sen vaihteluista 1994–2006.”, in Finnish, Helsinki 2007. 88 s. Sosiaali- ja terveysministeriön selvityksiä 2007:28.

Vuorenkoski L. (2008) Finland Health system review. *Health Systems in Transition*. **10** (4). http://www.euro.who.int/data/assets/pdf_file/0007/80692/E91937.pdf

Wimo, A, Jönsson, L, Bond, J, Prince, M and Winblad, B (2013) The worldwide economic impact of dementia. *Alzheimer's & Dementia*, **9**, 1-11.

World Health Organization: International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization, (2013) (accessed April 10, 2013]. <http://apps.who.int/classifications/icd10/browse/2010/en>.

World Health Organization (1990) Cancer Pain Relief and Palliative Care. Technical Report Series 804. Geneva: World Health Organization; 1990.

Wu, Y.T., Matthews, F. E., and Brayne, C. (2014) Dementia: time trends and policy responses. *Maturitas*, **79** (2), 191-195.

Zweig, S. C. (1997) Cardiopulmonary resuscitation and do-not-resuscitate orders in the nursing home. *Arch Fam Med*, **6** (5), 424-429.

APPENDIX

Appendix 1: Dementia (Alzheimer's Association, 2013 Facts and Figures)

Common types of dementia and their typical characteristics

Type of dementia	Characteristics
AD	<p>Most common type of dementia; accounts for an estimated 60% to 80% of cases.</p> <p>Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes, and difficulty speaking, swallowing, and walking.</p> <p>New criteria and guidelines for diagnosing AD were proposed and published in 2011. They recommend that AD be considered a disease that begins well before the development of symptoms.</p> <p>Hallmark brain abnormalities are deposits of the protein fragment amyloid beta (plaques) and twisted strands of the protein tau (tangles), as well as evidence of nerve cell damage and death in the brain.</p>
Vascular dementia	<p>Previously known as multi-infarct or poststroke dementia, vascular dementia is less common as a sole cause of dementia than AD.</p> <p>Impaired judgment or ability to make plans is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of AD.</p> <p>Vascular dementia occurs because of brain injuries such as microscopic bleeding and blood vessel blockage. The location of the brain injury determines how the individual's thinking and physical functioning are affected.</p> <p>In the past, evidence of vascular dementia was used to exclude a diagnosis of AD (and vice versa). That practice is no longer considered consistent with pathological evidence, which shows that the brain changes of both types of dementia can be present simultaneously. When any two or more types of dementia are present at the same time, the individual is considered to have mixed dementia.</p>
DLB	<p>People with DLB have some of the symptoms common in AD, but are more likely than people with AD to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.</p> <p>Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also aggregates in the brains of people with PD, but the aggregates may appear in a pattern that is different from DLB.</p> <p>The brain changes of DLB alone can cause dementia, or they can be present at the same time as the brain changes of AD and/or vascular dementia, with each entity contributing to the development of dementia. When this happens, the individual is said to have mixed dementia.</p>
FTLD	<p>Includes dementias such as behavioral-variant FTLT, primary progressive aphasia, Pick's disease, and progressive supranuclear palsy.</p> <p>Typical symptoms include changes in personality and behavior, and difficulty with language.</p> <p>Nerve cells in the front and side regions of the brain are especially affected. No distinguishing microscopic abnormality is linked to all cases.</p> <p>The brain changes of behavioral-variant FTLT may be present at the same time as the brain changes of AD, but people with behavioral-variant FTLT generally develop symptoms at a younger age (at about age 60) and survive for fewer years than those with AD.</p>
Mixed dementia	<p>Characterized by the hallmark abnormalities of AD and another type of dementia—most commonly vascular dementia, but also other types, such as DLB.</p> <p>Recent studies suggest that mixed dementia is more common than previously thought.</p>
PD	<p>As PD progresses, it often results in a severe dementia similar to DLB or AD.</p> <p>Problems with movement are a common symptom early in the disease.</p> <p>Alpha-synuclein aggregates are likely to begin in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine.</p> <p>The incidence of PD is about one-tenth that of AD.</p>
Creutzfeldt-Jakob disease	<p>Rapidly fatal disorder that impairs memory and coordination, and causes behavior changes.</p> <p>Results from an infectious misfolded protein (prion) that causes other proteins throughout the brain to misfold and thus malfunction.</p> <p>Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.</p>
Normal pressure hydrocephalus	<p>Symptoms include difficulty walking, memory loss, and inability to control urination.</p> <p>Caused by the buildup of fluid in the brain.</p> <p>Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.</p>

Abbreviations: AD, Alzheimer's disease; DLB, Dementia with Lewy bodies; FTLT, Frontotemporal lobar degeneration; PD, Parkinson's disease.

Appendix II

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)

Psychiatric Diagnoses are categorized by the Diagnostic and Statistical Manual of Mental Disorders, 4th. Edition. Better known as the DSM-IV, the manual is published by the American Psychiatric Association and covers all mental health disorders for both children and adults. It also lists known causes of these disorders, statistics in terms of gender, age at onset, and prognosis as well as some research concerning the optimal treatment approaches.

Mental Health Professionals use this manual when working with patients in order to better understand their illness and potential treatment and to help 3rd party payers (e.g., insurance) understand the needs of the patient. The book is typically considered the ‘bible’ for any professional who makes psychiatric diagnoses in the United States and many other countries. Much of the diagnostic information on these pages is gathered from the DSM IV.

The DSM IV is published by the American Psychiatric Association. Much of the information from the Psychiatric Disorders pages is summarized from the pages of this text. Should any questions arise concerning incongruences or inaccurate information, you should always default to the DSM as the ultimate guide to mental disorders.

The DSM uses a multiaxial or multidimensional approach to diagnosing because rarely do other factors in a person’s life not impact their mental health. It assesses five dimensions as described below:

Axis I: Clinical Syndromes

This is what we typically think of as the diagnosis (e.g., depression, schizophrenia, social phobia)

Axis II: Developmental Disorders and Personality Disorders

Developmental disorders include autism and mental retardation, disorders which are typically first evident in childhood

Personality disorders are clinical syndromes which have a more long lasting symptoms and encompass the individual's way of interacting with the world. They include Paranoid, Antisocial, and Borderline Personality Disorders.

Axis III: Physical Conditions

Physical conditions, which play a role in the development, continuance, or exacerbation of Axis I and II Disorders

Physical conditions such as brain injury or HIV/AIDS that can result in symptoms of mental illness are included here.

Axis IV: Severity of Psychosocial Stressors

Events in a person's life, such as death of a loved one, starting a new job, college, unemployment, and even marriage can impact the disorders listed in Axis I and II. These events are both listed and rated for this axis.

Axis V: Highest Level of Functioning

On the final axis, the clinician rates the person's level of functioning both at the present time and the highest level within the previous year. This helps the clinician understand how the above four axes are affecting the person and what type of changes could be expected.

DSM-IV (1994)

In 1994, DSM-IV was published, listing 297 disorders in 886 pages. The task force was chaired by Allen Frances. A steering committee of 27 people was introduced, including four psychologists. The steering committee created 13 work groups of five to 16 members. Each work group had about 20 advisers. The work groups conducted a three-step process: first, each group conducted an extensive literature review of their diagnoses; then, they requested data from researchers, conducting analyses to determine which criteria required change, with instructions to be conservative; finally, they conducted multicenter field trials relating diagnoses to clinical practice. A major change from

previous versions was the inclusion of a clinical significance criterion to almost half of all the categories, which required that symptoms cause "clinically significant distress or impairment in social, occupational, or other important areas of functioning". Some personality disorder diagnoses were deleted or moved to the appendix.

DSM-IV-TR (2000)

A "text revision" of the DSM-IV, known as the DSM-IV-TR, was published in 2000. The diagnostic categories and the vast majority of the specific criteria for diagnosis were unchanged. The text sections giving extra information on each diagnosis were updated, as were some of the diagnostic codes to maintain consistency with the ICD. The DSM-IV-TR was organized into a five-part axial system. The first axis incorporated clinical disorders. The second axis covered personality disorders and intellectual disabilities. The remaining axes covered medical, psychosocial, environmental, and childhood factors functionally necessary to provide diagnostic criteria for health care assessments.

The DSM-IV-TR characterizes a mental disorder as "a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual [which] is associated with present distress... or disability... or with a significant increased risk of suffering." It also notes that "no definition adequately specifies precise boundaries for the concept of 'mental disorder'... different situations call for different definitions". It states that "there is no assumption that each category of mental disorder is a completely discrete entity with absolute boundaries dividing it from other mental disorders or from no mental disorder" (APA, 1994 and 2000). There are attempts to adjust the wording for the upcoming DSM-V.

DSM-5 (2013)

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), the DSM-5, was approved by the Board of Trustees of the APA on December 1, 2012. Published on May 18, 2013, the DSM-5 contains extensively revised diagnoses and, in some cases, broadens diagnostic definitions while narrowing definitions in other cases. The DSM-5 is the first major edition of the manual in twenty years.^[41]

A significant change in the fifth edition is the deletion of the subtypes of schizophrenia (paranoid, disorganized, catatonic, undifferentiated and residual).

The deletion of the subsets of autistic spectrum disorder (namely, Asperger's Syndrome, classic autism, Rett Syndrome, Childhood Disintegrative Disorder and pervasive developmental disorder not otherwise specified) was also implemented, with specifiers with regard to intensity (mild, moderate and severe). Severity is based on social communication impairments and restricted, repetitive patterns of behaviour, with three levels: 1 (requiring support), 2 (requiring substantial support) and 3 (requiring very substantial support).

During the revision process, the APA website periodically listed several sections of the DSM-5 for review and discussion.